DOCUMENT RESUME

ED 267 895 PS 015 676

TITLE	Sudden Infant Death Syndrome. Joint Hearing before Certain Subcommittees of the Committee on Post Office and Civil Service and the Committee on Energy and Commerce and the Select Committee on Children, Youth, and Families. House of Representatives, Ninety-Ninth Congress, First Session, November 14, 1985.
INSTITUTION	Congress of the U.S., Washington, DC. House Committee on Energy and Commerce.; Congress of the U. S., Washington, D. C. House Committee on Post Office and Civil Service.; Congress of the U.S., Washington, DC. House Select Committee on Children, Youth, and Families.
PUB DATE	14 Nov 85
NOTE	114p.; Serial No. 99-40 and 99-52. Document contains small print.
AVAILABLE FROM	Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402.
PUB TYPE	Legal/Legislative/Regulatory Materials (090)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	*Block Grants; *Diseases; Financial Needs; Financial Support; Hearings; Incidence; *Infant Mortality; Profiles; *Research Needs; State Programs
IDENTIFIERS	Congress 99th; *Research Results; *Sudden Infant Death Syndrome

ABSTRACT

Testimony in this congressional hearing focused on the sudden infant death syndrome (SIDS), the major cause of death in infants over 1 month of age in the United States. Three panels of witnesses, comprised of concerned parents, academicians, and national and regional officers of service organizations, (1) provide an overview of the research and clinical perspectives on SIDS, (2) report on the federal government's research program effort, (3) discuss block grants and SIDS-related counseling services, (4) describe the use of home infant health monitoring devices, and (5) share the experiences of parents who have lost their children to SIDS. Also included in the transcript are the statement of Lewis P. Lipsitt, Professor of Psychology and Medical Science, Brown University, summarizing what is currently known about the syndrome, facts about the status of SIDS services in the states, and the Comptroller General's report to Congress concerning the effect of block grants on sudden infant death syndrome services. (RH)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

PS

SUDDEN INFANT DEATH SYNDROME

ED267895

JOINT HEARING

BEFORE CERTAIN

SUBCOMMITTEES

OF THE

COMMITTEE ON
POST OFFICE AND CIVIL SERVICE

AND THE

COMMITTEE ON ENERGY AND COMMERCE

AND THE

SELECT COMMITTEE ON
CHILDREN, YOUTH, AND FAMILIES
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

NOVEMBER 14, 1985

Serial No. 99–40
(Committee on Post Office and Civil Service

Serial No. 99–52
(Committee on Energy and Commerce)

PS 015676

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

☒ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

- Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

U.S. GOVERNMENT PRINTING OFFICE
57-412 O WASHINGTON : 1986

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, D.C. 20402

COMMITTEE ON POST OFFICE AND CIVIL SERVICE

WILLIAM D. FORD, Michigan, *Chairman*

WILLIAM (BILL) CLAY, Missouri	GENE TAYLOR, Missouri
PATRICIA SCHROEDER, Colorado	BENJAMIN A. GILMAN, New York
STEPHEN J. SOLARZ, New York	CHARLES PASHAYAN, Jr., California
ROBERT GARCIA, New York	FRANK HORTON, New York
MICKEY LELAND, Texas	JOHN T. MYERS, Indiana
GUS YATRON, Pennsylvania	DON YOUNG, Alaska
MARY ROSE OAKAR, Ohio	JAMES V. HANSEN, Utah
GERRY SIKORSKI, Minnesota	DAN BURTON, Indiana
FRANK McCLOSKEY, Indiana	
GARY L. ACKERMAN, New York	
MERVYN M. DYMALLY, California	
RON de LUGO, Virgin Islands	
MORRIS K. UDALL, Arizona	

Tom DeYulia, *Staff Director*
Robert E. Lockhart, *General Counsel*
Patricia F. Rissler, *Deputy Staff Director and Chief Clerk*
Joseph A. Fisher, *Minority Staff Director*

Subcommittee on Census and Population

ROBERT GARCIA, New York, *Chairman*

MARY ROSE OAKAR, Ohio	JAMES V. HANSEN, Utah
GARY L. ACKERMAN, New York	JOHN T. MYERS, Indiana

Lillian Fernandez, *Subcommittee Staff Director*

COMMITTEE ON ENERGY AND COMMERCE

JOHN D. DINGELL, Michigan, *Chairman*

JAMES H. SCHEUER, New York
HENRY A. WAXMAN, California
TIMOTHY E. WIRTH, Colorado
PHILIP R. SHARP, Indiana
JAMES J. FLORIO, New Jersey
EDWARD J. MARKEY, Massachusetts
THOMAS A. LUKEN, Ohio
DOUG WALGREN, Pennsylvania
BARBARA A. MIKULSKI, Maryland
AL SWIFT, Washington
MICKEY LELAND, Texas
RICHARD C. SHELBY, Alabama
CARDISS COLLINS, Illinois
MIKE SYNAR, Oklahoma
W.J. (BILLY) TAUZIN, Louisiana
RON WYDEN, Oregon
RALPH M. HALL, Texas
DENNIS E. ECKART, Ohio
WAYNE DOWDY, Mississippi
BILL RICHARDSON, New Mexico
JIM SLATTERY, Kansas
GERRY SIKORSKI, Minnesota
JOHN BRYANT, Texas
JIM BATES, California

JAMES T. BROYHILL, North Carolina
NORMAN F. LENT, New York
EDWARD R. MADIGAN, Illinois
CARLOS J. MOORHEAD, California
MATTHEW J. RINALDO, New Jersey
WILLIAM E. DANNEMEYER, California
BOB WHITTAKER, Kansas
THOMAS J. TAUKE, Iowa
DON RITTER, Pennsylvania
DAN COATS, Indiana
THOMAS J. BLILEY, Jr., Virginia
JACK FIELDS, Texas
MICHAEL G. OXLEY, Ohio
HOWARD C. NIELSON, Utah
MICHAEL BILIRAKIS, Florida
DAN SCHAEFER, Colorado
FRED J. ECKERT, New York

WM. MICHAEL KITZMILLER, *Staff Director*
SHARON E. DAVIS, *Chief Clerk/Administrative Assistant*
DONALD A. WATT, *Printing Editor*
ARNOLD I. HAVENS, *Minority Counsel*

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

HENRY A. WAXMAN, California, *Chairman*

JAMES H. SCHEUER, New York
DOUG WALGREN, Pennsylvania
RICHARD C. SHELBY, Alabama
RON WYDEN, Oregon
GERRY SIKORSKI, Minnesota
TIMOTHY E. WIRTH, Colorado
JAMES J. FLORIO, New Jersey
THOMAS A. LUKEN, Ohio
BARBARA A. MIKULSKI, Maryland
MICKEY LELAND, Texas
CARDISS COLLINS, Illinois
BILL RICHARDSON, New Mexico
JIM BATES, California
JOHN D. DINGELL, Michigan
(Ex Officio)

EDWARD R. MADIGAN, Illinois
WILLIAM E. DANNEMEYER, California
BOB WHITTAKER, Kansas
THOMAS J. TAUKE, Iowa
DON RITTER, Pennsylvania
THOMAS J. BLILEY, Jr., Virginia
HOWARD C. NIELSON, Utah
MICHAEL BILIRAKIS, Florida
FRED J. ECKERT, New York
JAMES T. BROYHILL, North Carolina
(Ex Officio)

KAREN NELSON, *Staff Director*
TIMOTHY WESTMORELAND, *Assistant Counsel*
RUTH KATZ, *Assistant Counsel*
ELLEN RIKER, *Minority Staff Associate*

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

GEORGE MILLER, California, *Chairman*

WILLIAM LEHMAN, Florida
PATRICIA SCHROEDER, Colorado
LINDY BOGGS, Louisiana
MATTHEW F. McHUGH, New York
TED WEISS, New York
BERYL ANTHONY, Jr., Arkansas
BARBARA BOXER, California
SANDER M. LEVIN, Michigan
BRUCE A. MORRISON, Connecticut
J. ROY ROWLAND, Georgia
GERRY SIKORSKI, Minnesota
ALAN WHEAT, Missouri
MATTHEW G. MARTINEZ, California
LANE EVANS, Illinois

DAN COATS, Indiana
HAMILTON FISH, Jr., New York
THOMAS J. BLILEY, Jr., Virginia
FRANK R. WOLF, Virginia
DAN BURTON, Indiana
NANCY L. JOHNSON, Connecticut
JOHN R. McKERNAN, Jr., Maine
BARBARA F. VUCANOVICH, Nevada
DAVID S. MONSON, Utah
ROBERT C. SMITH, New Hampshire

COMMITTEE STAFF

ALAN J. STONE, *Staff Director and Counsel*
ANN ROSEWATER, *Deputy Staff Director*
MARK SOUDER, *Minority Staff Director*

CONTENTS

Statements of: Page
- Jane Garcia 5
- Marie A. Valdes-Dapena, M.D., professor of pathology and pediatrics, University of Miami, and chairman and president, National SIDS Foundation; Frederick Mandell, M.D., clinical associate professor of pediatrics, Harvard University, and vice chairman, National SIDS Foundation; and Charlotte S. Catz, M.D., chief, pregnancy and perinatology branch, Center for Research for Mothers and Children, National Institute of Child Health and Human Development, National Institutes of Health; accompanied by Geraldine J. Norris, director of the National SIDS Program, Division of Maternal and Child Health, HRSA 8
  - Marie A. Valdes-Dapena 8
  - Frederick Mandell 26
  - Charlotte S. Catz 27
- Gayla Reiter, SIDS parent, and legislative coordinator for the Northern California Chapter, National SIDS Foundation; Carrie Sheehan, western regional director, National SIDS Foundation; and Parker H. Petit, chairman of the board, chief executive officer, and founder of Healthdyne, Inc 70
  - Gayla Reiter 70
  - Carrie Sheehan 79
  - Parker H. Petit 88
- Jennifer and Ken Wilkinson, SIDS parents, Great Falls, VA; and Sherry and Ronn Waller, SIDS parents, Dallas, TX 91
  - Jennifer Wilkinson 91
  - Ronn Waller 93

Opening statement of:
- Hon. Robert Garcia 1
- Hon. George Miller 2
- Hon. Thomas J. Bliley, Jr 4
- Hon. Henry A. Waxman 4

Statement submitted by:
- Lewis P. Lipsitt, professor of psychology and medical science, Brown University 97

Response to written questions received from:
- Geraldine Norris, director, SIDS Project, Health Resources and Services Administration 100

SUDDEN INFANT DEATH SYNDROME

THURSDAY, NOVEMBER 14, 1985

HOUSE OF REPRESENTATIVES, SUBCOMMITTEE ON CENSUS AND POPULATION, COMMITTEE ON POST OFFICE AND CIVIL SERVICE; SELECT COMMITTEE ON CHILDREN, YOUTH AND FAMILIES; AND SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT, COMMITTEE ON ENERGY AND COMMERCE,

Washington, DC.

The committees met in joint session, pursuant to call, at 10:08 a.m., in room 304, Cannon House Office Building, Hon. Robert Garcia (chairman of the Subcommittee on Census and Population, Committee on Post Office and Civil Service) presiding.

Mr. GARCIA. I would like to welcome all of you here to the hearing on sudden infant death syndrome, also known as SIDS. I appreciate my colleague, Congressman George Miller, who is the chairman of the Select Committee on Children, Youth and Families, for being here. I would like to thank Congressman Henry Waxman, who is the chairman of the Subcommittee on Health and the Environment, and I would also like to thank my colleague from Indiana, Mr. Coats, and my colleague from Georgia, Mr. Rowland, for joining us this morning. I might add that Congressman Rowland is also Dr. Rowland, M.D. And I see Congressman Bliley of Virginia has just entered.

First I would like to take this opportunity to thank all my colleagues for joining us on this very important hearing. The subject of SIDS is obviously very difficult to talk about. Death, in general, is difficult to talk about, but we are here today because it is critically necessary to talk about sudden infant death syndrome, the major cause of death of infants over one month of age in the United States.

Because of SIDS, 7,000 apparently healthy babies die each year. During this year more infants will die of SIDS than will succumb to cystic fibrosis, childhood cancer, childhood heart disease, and child abuse combined. This devastating syndrome comes on suddenly, without warning, strikes its victims indiscriminately, whether they are black, white, Hispanic, or Asian, whether they are rich or poor.

The victims of SIDS are not only the babies but also the families. The families of babies who die of SIDS undergo severe feelings of guilt, fearing that perhaps they might have done something wrong. To make matters worse, because the public does not have a clear understanding of sudden infant death syndrome, the public may suspect the victims' families of child abuse or neglect. Much more education and research is critically needed on SIDS to alleviate the confusion and additional suffering caused by this syndrome.

Last year my wife and I lost a grandson to SIDS. It was a tragic and helpless situation. But as I told others what had happened to me and my family, I began to realize that we were not alone. A number of other persons I met had either lost a child or a relative to SIDS, or knew someone who had. That is one of the reasons we are holding this hearing, to let people know that they are not alone, that something must be done to fight SIDS.

It concerns me deeply that during the past four years funding for the education and research on SIDS has been drastically and, I believe, disproportionately reduced, while there has not been any decrease in the number of SIDS-related deaths. I hope that through our hearing we can come to a better understanding of sudden infant death syndrome, a better understanding of the need for additional funding for research and education, and a better understanding of the impact of SIDS on the families who have lost their babies by this dreaded syndrome.

I thank you very much for being with us this morning. I would like to call on my colleague from California, the chairman of the Select Committee on Youth, Congressman Miller of California.

Mr. MILLER. Thank you, Congressman Garcia. I thank you also for joining in and leading the way on these hearings and I look forward to hearing from the witnesses. I hope what will emerge at the end of these hearings is a consensus by the membership of these three committees that we will have the ability to try and conquer this very, very unfortunate disease, should we decide to do so. I hope that the decision will be made by the membership of these committees, to go to the full House and to ask that we maintain and improve our research effort on behalf of these families and these infants.

I also want to welcome one of our witnesses, Gayla Reiter, who has been very, very active in the Northern California SIDS Foundation, and whom we will hear from later. I think she will tell us some of the problems that we're encountering in trying to maintain primary research in this area.

Thank you.

Mr. GARCIA. Thank you. My colleague from Indiana, Mr. Coats.

Mr. COATS. Thank you, Mr. Chairman. As the ranking Republican member of the House Select Committee on Children, Youth and Families, and as a cosponsor of House Joint Resolution 322, which was introduced by Chairman Miller of our committee, I am pleased to be here this morning to help bring some attention to what I think is a very important subject and one which has tragically affected the lives of many, many people.

I am sure that this morning's testimony will highlight what is currently known about the causes of SIDS, its incidence and possible fruitful lines for further research. I welcome the testimony that we're about to hear because I believe that increased public awareness and sensitivity to the tragedy of this problem will help grieving parents cope with this situation. Increased attention to the problem will perhaps stimulate major research centers to do more research into the causes of sudden infant death syndrome and identify those infants at risk. Clearly, research needs to be done that would establish the necessary relationships to be able to predict individual vulnerabilities toward this syndrome.

All of us, I believe, are hopeful that this research would include an exploration into the number of prevention activities and approaches that would reduce the number of SIDS cases per year.

We, in Congress, should not have to be convinced—and I don't think most of us need to be convinced—of the tragedy of SIDS. Rather, I believe the focus today ought to be on what we can really do to prevent this tragedy from occurring in ever increasing incidences.

Those of us who care strongly about this issue are going to have to ask some difficult questions about funding priorities. I raise the funding issue not because we don't care but precisely because we care so much. I don't want to sugar-coat the funding aspect because that, in itself, would be a tragedy. But if we are to get more than promises out of this hearing, then we need to know about the prospects for and progress toward reducing the number of SIDS cases.

What have we learned in the past 10 or 15 years of research that could guide future efforts and justify adequate funding for these efforts? It appears that what little is known today about SIDS shows that it is related to prenatal conditions, so the research that is funded for high-risk infancy and high-risk pregnancy ought to lend some insight into the causes of SIDS. Has this been the case? What has been learned from the high-risk infancy and pregnancy research that is relevant to SIDS?

Let me today challenge the expert witnesses who will testify before us to not merely list all the activities they would like to see funded, but also to prioritize their ideas. A priority list of what ought to be done to make SIDS preventable is critical if support is to follow. What is the best thing we should do with the dollars that we have available.

Finally, I sincerely hope that this hearing will contribute to the public awareness about the tragedy of sudden infant death syndrome, that it will inform and stimulate private university medical centers to engage in research that identifies the causes of SIDS and develop appropriate diagnostic tools to predict which infants are prone to develop this disease. But most important of all, I hope by focusing attention on sudden infant death syndrome that we can offer some comfort to parents that the American people do care about these victims and want to find a cure for this baffling and tragic disease.

Mr. GARCIA. Congressman Rowland.

Dr. ROWLAND. Thank you, Mr. Chairman. I commend you and Chairman Miller for having this hearing, and also Mr. Coats. I think it is so very important.

You talk about the tragedy of this particular disease—and I assume it is a disease; we'll learn more about that as we go along. If you wake up in the morning and find what you thought was an apparently healthy child dead in the crib, it is almost unexplainable the amount of distress that this brings on a family. As a physician, I have personally witnessed this type of situation and I can tell you it is terrible.

It is a very perplexing problem. We're just beginning to make, I think, some inroads into the causes of it. I think it is going to take a lot of research because it is so evasive. It is so difficult to determine why it is happening, and it is going to take a long time to determine the causes.

I think it is very important for us to be involved here in supplying whatever help we can in reaching into this area and learning more about it. I commend the people who are here this morning also for coming and all that you do to try to find out just what is taking place.

Thank you, Mr. Chairman.

Mr. GARCIA. Mr. Bliley.

Mr. BLILEY. Thank you, Mr. Chairman. I want to thank you and Chairman Miller for arranging this hearing. Since we have a limited amount of time and we have so many people here to testify, I will submit my statement for the record.

Mr. GARCIA. Without objection.

[The statement of Hon. Thomas J. Bliley, Jr. follows:]

STATEMENT OF HON. THOMAS J. BLILEY, JR.

Mr. Chairman, I appreciate the opportunity to participate in this joint hearing to learn more about how we are combating the serious problem of Sudden Infant Death Syndrome (SIDS). I am here as a member of two of the three Subcommittees sponsoring this hearing and that fact indicates the depth of my concern about the health of our children.

SIDS is a terrible affliction in its destruction of the life of many innocent infants and in the impact that it can have on the families of the victims. Approximately 7,000 infants die of SIDS every year. Because there is no certain explanation of what causes SIDS or what we can do to prevent its occurrence, there is a great deal of misunderstanding and fear attached to it. The inability of physicians to detect symptoms of SIDS or to prevent it other than by monitoring, cause many new parents to have an inordinate fear of SIDS. The anxiety caused by worrying excessively about this problem and the guilt feelings of parents who have lost children to SIDS often cause other severe problems in family relationships.

I applaud the three Subcommittees for holding this hearing. I look forward to the testimony and I anticipate joining in further action that may be necessary at the Congressional level to end the terror and the family destruction that can be caused by Sudden Infant Death Syndrome.

Mr. GARCIA. Also, without objection, we will insert into the record at this point the statement of Congressman Waxman, chairman of the Subcommittee on Health and the Environment, Committee on Energy and Commerce.

[The statement of Hon. Henry A. Waxman follows:]

STATEMENT OF HON. HENRY A. WAXMAN, CHAIRMAN, SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

The birth of a healthy, happy baby is among life's greatest gifts. It's a moment that couples hope for, plan for, and work for. And it's a moment that couples expect to become—literally—a lifetime of joy as they watch their baby grow to adulthood and perhaps, like themselves, to parenthood.

But for thousands of families, this moment is never fulfilled. Instead, it is cut short by an unexpected and unexplained killer known as Sudden Infant Death Syndrome or "SIDS." This condition strikes its victims quietly, quickly, and seemingly without pain. But for their parents, the pain is inmeasurable and it never goes away.

Today's joint hearings are on SIDS—on what we already know and on what we still need to know—about this tragic and traumatic disease.

Through the work of the National Institutes of Health and private foundations, promising research work is well underway. And through the maternal and child health block grant, States are able to provide counseling services to SIDS families and education services to the general public.

These efforts have been helpful, but they have not been enough:

Federal research dollars into the cause of SIDS have declined significantly during the last several years. Yet over 7,000 babies die of SIDS each year. SIDS each year. SIDS continues to be is the number one cause of death in infants after the first week of life. It kills more babies in their first year than child abuse, cystic fibrosis, car accidents, and cancer combined.

Because of cutbacks brought about through the development of the maternal and child health block grant, the GAO has reported that the number of States providing SIDS-related programs has decreased. Some States have reduced the type or amount of service they offer; others have been forced to drop their programs altogether. Few, if any, new programs have been started.

We must do better than this. And we can do better than this. But with limited financial resources, the job won't be easy. Today's hearings mark the beginning, however, and I am pleased that the Subcommittee on Health and the Environment is participating in this effort.

Progress may be slow, but it can be made. That special moment of birth should become a lifetime of joy for all babies and their families. We can make that happen. And with the guidance of today's expert witnesses, I am confident we will make that happen.

Mr. GARCIA. My wife and I just flew in this morning from New York City. On the flight I asked her if she wanted to testify and relate to this committee and for the record the actual experiences that we experienced as grandparents when we lost our grandchild Alex just about a year ago. I do appreciate the panel giving me this opportunity to let my wife testify.

Jane, why don't you proceed.

STATEMENT OF JANE GARCIA

Mrs. JANE GARCIA. Thank you, Mr. Chairman.

I am a member of this panel and a member of the board of the National Sudden Infant Death Syndrome Foundation as a result of the loss of our grandchild. This group has been extremely instrumental in helping all of us, my husband and my family, to find some stability and, obviously, our own faith is the other factor.

Edward Alexander Power was born August 14, 1983, and he died December 11, 1984. That's 16 months. We often question ourselves, and still do today, why this child only spent such a brief period of time with us. I think that, if for no other reason, his coming into the world and his leaving have made it possible for other people to suffer less and to understand more what has happened to them with a crib death or SIDS. Perhaps it wasn't in vain.

My husband and I were on a congressional delegation in South America with the Congressional Hispanic Caucus. We were in Peru, and Bob was waiting to see the President of Peru. He received a call from our son that there was an emergency. The emergency was that our grandson was in the hospital and he was dead. They had been able to resuscitate him artificially—his heart was beating—but he was brain dead.

It took us 24 hours to get from Lima, Peru, to Albany, where they were. When we arrived, we only had to look at that child 1 minute to realize that he was not with us any more, in spite of the heroic efforts of every doctor available. Specialists and pediatricians were gathered around. Our son and daughter-in-law were so devastated because it was so completely incomprehensible.

My daughter-in-law had a very normal pregnancy. She was attended by a physician continuously. She didn't smoke or drink or gain too much weight or too little weight. It was all perfectly fine. The child was born by caesarean section but was a perfectly normal child. He never was sick. He had two colds in his life and a very sunny disposition.

And yet she went to work one morning and the child was put down for a nap, and an hour later, when he was to be woken up, he was dead. There was no accident, there was no poisoning, there was no sign of anything untoward.

An autopsy was done locally and tissues were sent to Mount Sinai Medical, because my husband is on the board of directors there. We tried to use every available resource. The answer was always the same—SIDS. I raised four children and I never heard of it. This was my first introduction.

There is something so unnatural about a child's coffin, and there is something so completely unnatural about a child dying, because this is the beginning of life. There is no way I can communicate to anyone in this room the absolute devastation felt by us, as parents, to watch your child suffer in a way that is absolutely unknown, blaming himself, taking to drink; a boy who doesn't drink, would go out at night and sit with a bottle of brandy and go away from everyone.

We all had deep religious experiences that brought us together again. In the wake of all of this, the only outlet for us was to talk about it, because there was no other thing to do.

The first communication that we had from anyone else relatively soon after the loss of this child was from the National Sudden Infant Death Foundation. Their chapter in Albany came to our rescue. At first we rejected them because we didn't want to believe that Alex had died of sudden infant death. There had to be another explanation, a more rational explanation, an explanation that perhaps the doctors couldn't find right away. But as time passed we realized that this was the medical answer and we had to accept it or we were going to go crazy.

Then my daughter-in-law began to give me the literature. She works in the Albany mental health facility and is more attune to medical issues. She was searching for a reason as well, so I think she was the first person to react to this in a normal way. She was the first person to introduce me to the foundation and their work. She found it a consolation—I could see she did—so I felt it was important that I follow suit.

But the word of mouth is what really brought to my satisfaction that we were not alone as a family. In talking to people, rarely did a conversation come up that somebody that I spoke to, or that Bob spoke to, or my son and daughter-in-law spoke to, did not have an experience in their family or did not know of one. I began to think that this is an extraordinarily prevalent thing in this day and age, with all the modern technical advances that we have, that children are dying, and they are dying for no apparent reason. We don't know the reasons.

My husband and I went to Spain on a mission in August, we were quite unprepared. I had left my suitcase in New York and was unable to pick it up. When I got to the conference in Toledo, I didn't have any clothes to change into, and we were going to be there for about 3 days. So the former mayor's wife came to my rescue and said she would take me to some stores.

I don't remember how the conversation came up. The first store we went into was a combination lingerie and infant store. In the interim, my daughter-in-law had been pregnant during this whole ordeal. But God in his infinite wisdom apparently knew what he was doing and sent us another healthy child, and we hope that nothing happens to him. He is 6 months old now.

As a grandmother, naturally I spend an inordinate amount of time thinking about my grandchild. So, in seeing this infant store, I said, "Oh, there's some clothes there, and I want to see some baby clothes." We got to talking, and she asked "This is your first grandchild?" I said, "Well, yes and no," and I started to tell her the story. She looked at me in the most pained way, really quite shocked, and I thought she was, you know, overreacting to my feelings. And she said, "I lost a child, too. I lost a child 6 years ago who was only 45 days old."

We went to another store, and she warned me that the woman in the store had recently lost a child. I was really surprised to hear—because I thought we had a rather unique experience, where Alex was 16 months old, and most of the children you read about or hear about are a few months old, or a few days old, which is one of the reasons why we wanted to reject this from our mind that it was possible.

There were the three of us in Toledo, Spain, sitting on the floor of a small boutique, talking about sudden infant death and how it had changed our lives, all of us, and what we were doing about it. That galvanized them into thinking what they could be doing in their town to organize, or perhaps in Spain to organize what they call "Muerte Subita de Infante."

I tell that just as an anecdote because I think at that moment I realized how important it was and that is the reason I'm here. I am not submitting a written testimony because I don't think I could do this twice, write it and then read it.

I think the most important thing we have to get out is the fact that this can happen to anyone, under any set of circumstances and at any time. I know that Congressman Rowland, a medical doctor, knows that that's true. You are totally unaware. We don't know enough about this to know what we can do to prevent it. A child that goes to a pediatrician every month, and the pediatrician cannot anticipate that he's going to be dead the next day. I think this is a very serious thing and all of us in this room and all of us in this country and all of us in this world should be concerned. No child is out of danger until we have a cure. To get there we must provide research tools, whether it be money, people or organizations to eradicate this completely in the 20th century. There should be no crib deaths.

Thank you very much.

Mr. GARCIA. Thank you very much, Jane.

We have been joined by some other Members of Congress. Mr. McKernan of Maine, Mr. Walgren from Pennsylvania, and Congressman Wolf from Virginia. Congresswoman Schroeder was here as well as Congressman Sikorsky of Minnesota.

Today we have three panels of witnesses. Our first panel is comprised of Dr. Marie Valdes-Dapena, professor of pathology and pediatrics, University of Miami, and chairman and president of the National SIDS Foundation; Dr. Frederick Mandell, who is clinical associate professor of pediatrics from Harvard University, and the vice chairman of the National SIDS Foundation; and Dr. Charlotte S. Catz, who is chief of the Pregnancy and Perinatology Branch, Center for Research for Mothers and Children, National Institute of Child Health and Human Development.

Dr. Dapena and Dr. Mandell will provide us an overview of the research and clinical perspectives on SIDS, and Dr. Catz will update us on the Federal Government's research program effort.

I guess we will start off with Dr. Valdes-Dapena.

STATEMENT OF MARIE A. VALDES-DAPENA, M.D., PROFESSOR OF PATHOLOGY AND PEDIATRICS, UNIVERSITY OF MIAMI, AND CHAIRMAN AND PRESIDENT, NATIONAL SIDS FOUNDATION

Dr. VALDES-DAPENA. Thank you, Mr. Garcia.

Ladies and gentlemen, people in Miami call me Dr. Dapena. I am professor of pathology and pediatrics at the University of Miami School of Medicine.

I have been engaged in research in the area of crib death for the last 27 years, and I have watched our concept concerning that phenomenon change 180 degrees in those almost 3 decades. There is no question but that we have made progress in our understanding of this entity, but we do have a way to go.

The elements of progress that are most evident to me, of course, concern anatomic pathology because that's the nature of my own work. We now know, as we did not 15 years ago, that these babies are structurally a little bit different from normal in very subtle ways that one can determine only in large groups of babies and with what are called morphometric studies, which is to say studying the tissues under a microscope.

There are three ways that stand out in which we're pretty sure they look different from normal at autopsy. One of those is the fact that they do retain what is called baby fat around the adrenals. Exactly how that is to be interpreted no one knows.

Second, they are continuing to make red blood cells in the liver, something which little babies are supposed to stop doing at the time they get born. These babies are still making red blood cells. Whether that means they are slightly anemic or not is unknown.

Last, and most importantly, these babies have changes in a certain part of the brain, the back part of the brain called the brainstem, which are pathological, another feature that wasn't recognized 25 years ago. They have an abnormal number of what are called glia cells, which is like scarring of the brainstem, in areas that are critical to the regulation of breathing, of the action of the heart, and of swallowing.

All of these are bits of new information that have shed light on the nature of the baby in an anatomical way.

Now, in addition to that, on account of studies which were launched by the National Institute of Child Health and Development in 1979, we know more about how these babies function differently from normal, but only when you look at them in large groups, which is what the NICHD did. They looked at 840 babies scattered in six centers across the country and they discovered that these babies in large numbers, if you look at them like that, are not thriving well in utero.

We had always thought back in the early days that they were perfectly healthy, bouncing baby children, and that there was nothing wrong. It was as though they were struck by lightening. In fact, that doesn't appear to be true at all. These are babies who suffer what is called intra-uterine growth retardation. They are born not at the 50th percentile but at the 40th percentile in regard to body weight and body length and head circumference. They are not quite up to snuff.

In addition, they continue to drop in all of those parameters during their short span of life. They drop behind control living infants appreciably, measurably, and to a statistically significant degree. They are not thriving quite so well as we had thought.

The difficulty is that you can't tell that one baby at a time. The population as a whole includes too many babies who have a little bit of growth failure. But we do recognize, when we look at them in large numbers, that they aren't quite doing as well as we had thought.

In addition, they differ from living babies, again as a group, in the way that they function on the first day of life. They have a more rapid heart rate, they breathe in a more rapid fashion, they are more often ill during their short lives, and they are more often hospitalized.

From the NICHD cooperative study we also know that there are differences in mothers, something we hadn't realized 20 years ago. The single mother who is most at risk is the teenager, and the women also at exceedingly high risk are women who smoke. All of these are new bits of information. So you can see that we have made appreciable progress in the last two decades.

But we have a way to go. It is difficult to understand how we're going to make it if we don't have enough money coming out of the NIH. In 1981, $3 million was available for SIDS-associated research. Last year, it was $600,000.

Now, one of the most important studies that has been done in recent times is that of Dr. Hannah Kinney at Boston Children's Hospital and at Harvard. It is she who is at the present time working on the brainstem to elucidate what is happening in the brainstem, what's going wrong with it, why it looks the way it looks. Her project for work on the brainstem, which is critical, was approved in October. She was applying for $300,000 a year for 3 years. Her project was approved and it got funded, but for half of the application—$150,000. She wanted $300,000 and I think that was not an inflated budget. If she had obtained that, it would have been half of all of the projected budget for last year.

Clearly, that isn't enough. We are not going to get good research done by highly qualified people unless they apply knowing there's a chance that they're going to get projects like that funded. They won't even apply. They won't show up if the money isn't there.

There are things that need to be done, and we know some of them now. One of the things we need to know is how to prevent this during pregnancy. Since the seeds are apparently sown in pregnancy, what can we do to prevent those adverse influences from occurring in the first place.

The second thing that needs to be done is a lot more work in the neurosciences. We don't even know what is normal in the growth and development of the brainstem in utero. There is a lot of work that needs to be done there, and it cannot be done by less than the best researchers in pediatric neuropathology.

Last, and most importantly, we still don't know how to identify the individual baby who is apt to die like this. We have a way to go and we have to have money to do it.

I thank you.

[The statement of Dr. Valdes-Dapena follows; also included are responses to written questions:]

TESTIMONY FOR HEARING
ON H.J. RESOLUTION 322

Subcommittee on Census and Population
Select Committee on Children, Youth and Families
Subcommittee on Health and the Environment

Thursday, November 14, 1985

Marie A. Valdes-Dapena, M.D.
Professor of Pathology and Pediatrics, University of Miami
Chairman and President, National SIDS Foundation

The sudden infant death syndrome or crib death is by definition the sudden, and unexpected death of an infant who has seemed well--which death remains unexplained following complete post-mortem examination. About 7,000 infants die in this manner, each year, in this country. And as far as can be ascertained that number is not diminishing.

There is probably more than one cause for the phenomenon and it seems likely that a few of those have already come to light, namely central apnea and infant botulism.

Although there have been no single, so-called break-throughs in research in this arena in the last 15 years, investigators around the world have succeeded--in that span of time--in clarifying much of what was unclear concerning SIDS as a whole.

In the mid-1970's excitement ran high when Dr. Alfred Steinschneider proclaimed spontaneous, repetitive episodes of not-breathing (or apnea) as being a major mechanism for causation. That hypothesis appealed greatly to pediatricians because it meant that they might, first of all, identify the susceptible baby (as he was having those episodes of not breathing--in the night) and intervene to save his life--with an in-home monitor.

That burst of enthusiasm resulted in two changes of direction. The first, for clinicians, was the widespread use of monitors in the home--as a service to families and the second was a marked change in the kinds of research undertaken, such that most of it now relates to this issue of the overlap between unexplained apnea and SIDS.

As far as service is concerned no one knows for certain whether or not in-home monitors have changed the SIDS death rate--or numbers. It is clear that they must be used when babies have life-threatening episodes but whether they have reduced the death rate among subsequent siblings, for example, or not--is as yet unknown. At the moment the decision to use a home monitor, in any given situation, is the pediatrician's. It depends upon his best judgement.

In the realm of research, there have been important spin-offs from investigations aimed at exploring that hypothesis. One is the discovery that apparently, when examined very carefully, the tissues of some SIDS victims at autopsy are a little different from normal. One of the most significant of these is the brainstem where control centers for breathing and heart action are located; the brain stems of SIDS victims do show slight but definite 'scarring'. This is a critical issue because of the location. That sort of lesion could be part of the cause or represent an effect, but the fact that it exists is significant and news to us all. Some very sophisticated work is underway now at Boston Children's Hospital to refine our understanding of this important research discovery.

One of the most exciting investigative developments in the last decade has been the conduct and completion of the NICHD Multicenter Cooperative Epidemiologic Study of SIDS which began in 1979. Employing six study centers scattered across the length and breadth of the nation, this work has brought to light detailed analyses of the lives of 840 validated crib death babies, and has provided, for comparison, two sets of living control infants--one matched for age only and the other for age, birth weight and race. All of the autopsies were performed during a period of 1½ years and then over the ensuing 2 years all of the historical and epidemiologic data concerning both the crib death babies and control infants were collected and the autopsies certified (or not) by a panel of forensic and pediatric pathologists.

This project is monumental and is currently providing us with the largest and most reliable body of epidemiologic information ever available. A few of the historical features of future victims have been reported thus far. Of special interest among them are the following:

(1) Regarding DPT (Diptheria - Pertussis - Tetanus) injections, control

infants had received *more* DPT shots in temporal proximity to the date in question than had crib death babies--suggesting that these immunizations are *not* (in any major way) related to the sudden infant death syndrome.

(2) The SIDS victims exhibited retardation of growth and development *prior* to birth confirming earlier impressions that the seeds of SIDS are planted during intra-uterine life.

(3) Crib death babies fell behind even ideally matched controls in regard to growth and development *after* birth--losing ground progressively the longer they lived--making it clear that, as a group, these infants are not thriving so well as we had thought.

(4) On the first day of life, the SIDS infants had:

a) a more rapid heart rate, and

b) more rapid respiration than controls indicating that they *function* differently in some ways--as soon as they are born.

(5) The 840 SIDS victims were:

a) more often ill—during their too short lives, and

b) more often hospitalized than were control infants.

It is true that the clinical manifestations of the infants *vulnerability* during the first days of life are so minor, so subtle, that even the most astute neonatologist cannot--at the present time--identify the individual potential victim. However, when such babies are studied retrospectively, by the hundreds, as in collaborative projects, it becomes apparent that many or most of these infants who subsequently die suddenly, unexpectedly, and inexplicably are indeed different from normal, in a few special ways, on the very day of birth.

We also know now that although anybody's baby can succumb to crib death, there are certain types of mothers who are more at risk than others. Above all else it is clear that SIDS occurs most frequently in lower socio-economic groups. Around the world--in every nation--it is the children of those mothers who are most deprived, socially and economically, who are most susceptible. In Australia, it is the children of the aborigines, and in our nation, of the native Americans. Race, in itself, is irrelevant--but mother's welfare is critical. We also know with certainty now that teenage mothers are much more vulnerable than women in their 20's and 30's and that smoking mothers are at substantially increased risk.

Because there is no sound evidence today that the numbers of crib deaths occurring annually in this country have diminished in the last decade, this new insight provides us with direction for the research which should be undertaken in the near future. Two avenues of investigation demand our attention: (1) the development of diagnostic capability to the point at which we will be able to identify these subtly different, slightly handicapped infants who are particularly susceptible--while they are still in the new born nursery, and (2) the preparation of a program of prevention based upon improvement of maternal well being.

The research required now, including (a) improvement of the pediatrician's diagnostic capability, (b) development of a plan for prevention and (c) further investigations of the central nervous system in these infants is expensive. It dictates an increase in federal support.

Federal Research Dollars Awarded for SIDS and SIDS Related Research Grants and Contracts (Listed in Millions of Dollars)

	Fiscal Year				
Category	1980	1981	1982	1983	1984
SIDS Specific	$ 2.704	$ 3.368	$ 2.763	$ 1.780	$ .657
High Risk Infancy	6.097	6.315	5.448	5.719	5.863
High Risk Pregnancy	8.095	9.083	8.254	9.073	10.664
TOTAL.	$16.896	$18.766	$16.465	$16.572	$17.184

JOINT HEARING ON SUDDEN INFANT DEATH SYNDROME (SIDS) BEFORE THE SUBCOMMITTEE ON CENSUS AND POPULATION OF THE COMMITTEE ON POST OFFICE AND CIVIL SERVICE, THE SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES, AND THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT OF THE COMMITTEE ON ENERGY AND COMMERCE - THURSDAY, NOVEMBER 14, 1985.

QUESTIONS ADDRESSED TO:

Marie A. Valdes-Dapena, M.D.

1. Is sudden infant death syndrome as much of a problem today as it was 10 years ago? Or, has the problem been diminishing in recent years?

   RESPONSE: The sudden infant death syndrome is indeed as much of a problem today as it was 10 years ago. According to all reliable data, the problem has not diminished in recent years. As examples, accurate records have been kept on SIDS deaths over the last decade in such locations as Aukland, New Zealand, King County, Washington, and Ulmstead County, Minnesota. These records reveal that the rate of SIDS (approximately 2 per 1000 live births) has remained the same over that period of time.

2. What kinds of activities and research would you advocate if SIDS were allocated five million dollars?

   RESPONSE: Like the official planning committee of the NICHD, I would look first to further research in the neurosciences--both morphologic and biochemical. I would also advocate further neurophysiologic studies of control of respiration and heart rate. As importantly, I would advocate research directed toward identification of the potential victim and toward identification of measures for prevention of those gestational or prenatal factors which seem to predispose the infant before birth.

3. What is the profile of a baby who would be a good candidate for monitoring for SIDS?

   RESPONSE: Examples of infants that are good candidates for monitoring for SIDS include:

   a. Infants who have experienced severe, life threatening episodes of apnea (breathing stoppage) during sleep, and who require resuscitation;
   b. Very low birthweight infants;
   c. Infants of opiate addicted mothers.

   These infants have a risk which is significantly greater than that of the population in general.

   There is research currently underway which attempts to develop screening tools that will identify infants, with or without symptoms, who are at risk for prolonged infantile apnea or for SIDS.

4. Currently, are there any diagnostic tests which assist physicians in determining potential SIDS victims?

   RESPONSE: Such tests are being explored at this time, but there are no reliable, valid screening tools currently available for mass application.

   As the result of investigations of large numbers of SIDS victims, it is important to note that researchers have discovered clinical abnormalities as early as the first day of life. But these clinical signs of infant vulnerability are, as yet, too subtle to allow the detection of the individual potential victim.

5. Now that the country is once again in the midst of a baby boom, are there any preventative measures that pregnant women and new mothers and fathers can utilize?

   RESPONSE: Pregnant women tend to worry about the welfare of their unborn babies. In the past two generations, their concern focused on the possibility of bearing a child with a birth defect. Nowadays crib death worries them too.

   Crib death, also known as the sudden infant death syndrome, is the sudden and unexpected death of an infant who has seemed well and whose death has remained unexplained after the performance of an adequate autopsy. Just as physicians have not found a way to obviate the great majority of birth defects; e.g., congenital heart disease, neither can they prevent crib death. We now know however that the risk of crib death is approximately 2 of every 1,000 babies born alive which means that 998 of those 1,000 infants will not be affected. As research advances our knowledge, we anticipate that prevention will become a reality.

6. What do you believe are the most promising areas of research to pursue today?

   RESPONSE: Please see response to question #2

7. Have there been or are there any private research efforts on SIDS? Are there any joint research efforts between the private organization(s) and the federal government?

RESPONSE: 7a) Private Research Efforts for the Sudden Infant Death Syndrome:

Organization	NO. OF PROPOSALS* Primary SIDS	NO. OF PROPOSALS* SIDS-Related
American Lung Association		6
March of Dimes	1	4
National Center for the Prevention of SIDS		1
National SIDS Foundation	8	1

*Documentation is provided on pages 6-10

7b) Joint research efforts supported by both private and federal funds:

1) Coping with a SIDS Loss: Psycho-Social Impact and Predictors of Adjustment

Camille Wortman, Ph. D.
Roxane Silver, Ph. D.
Institute for Social Research
University of Michigan
Ann Arbor, Michigan

This research began with a Student Research Fellowship awarded by the National SIDS Foundation to Roxane Silver and Jesus Fernandes under the supervision of Dr. Camille Wortman. The questionnaire used in the study was further refined with consultation of Carolyn Szybist, then Executive Director of the National SIDS Foundation. With this work as the base, Dr. Wortman and Dr. Silver then applied to the Bureau of Maternal and Child Health and were awarded a 6-year grant to pursue this research. The project is now in its last year.

2) A Quantitative Morphologic and Neurochemical Study of the Brainstem in SIDS

Hannah Kinney, M.D.
Department of Neurosciences
Children's Hospital Medical Center
Boston, Massachusetts

Beginning in the spring of 1984, the National SIDS Foundation began providing seed money for the preliminary research necessary for Dr. Kinney to make application for major federal funds from the National Institute of Child Health & Human Development to carry out this 5-year project of primary SIDS research.

NICHD has awarded a grant to Dr. Kinney for 50% of the support that the project calls for. The National SIDS Foundation will continue to interest its Chapters and other donors in continued support of this important research.

AMERICAN LUNG ASSOCIATION: SIDS-Related Research

Primary Emphasis: Respiratory Distress in Infants

1) Respiratory Disease in Pre-Term Infants--Role of Ureaplasma, Urealyticum and Mycoplasma Hominis

Richard L. Wasserman, M.D.
University of Texas Health Science Center
Dallas, Texas

2) Factors Controlling the Development of Anti-oxidant Enzyme System of the Fetal Lung--Identical to or Separate from the Control Factors of Surfactant Development

Allen D. Stiles, M.D.
Brigham & Women's Hospitals
Joint Program in Neonatology
Boston, Massachusetts

3) Ductus Arteriosus Therapy in Surfactant Treated Pre-term Baboons with Hyaline Membrane Disease

Mrinalini C. Rao, Ph.D.
Department of Physiology & Biophysics
University of Illinois--Chicago--Health Science Center
Chicago, Illinois

4) Non-invasive Determinant of Respiratory System Mechanics During Mechanical Ventilation for Acute Respiratory Failure

Carl A. Gruetter, Ph.D.
Department of Pharmacology
Marshall University School of Medicine
Huntington, West Virginia

5) Regulation of the Differentiation of Isolated Fetal Pneumocytes

Richard J. David, M.D.
Children's Memorial Hospital
Chicago, Illinois

6) The Role of Insulin in Secretory Process of Cultured Type 2 Cells

Martha Brunner, Ph.D.
Department of Physiology
School of Dentistry
University of Maryland
Baltimore, Maryland

MARCH OF DIMES: **SIDS & SIDS-related Research**

1) To learn whether a simple test of respiratory control mechanism in low weight newborns predicts individual risk for SIDS.

Carl E. Hunt, M.D.
Children's Memorial Hospital
Chicago, Illinois

2) To study a mechanism by which brief obstruction of the throat may inhibit the urge to breathe in premature babies and those at special risk for SIDS.

Oommen T. Mathew, M.D.
Department of Pediatrics
University of Texas Medical Branch
Galveston, Texas

3) To devise a test for vulnerability to life threatening and brain damaging episodes of airway obstruction in babies with Pierre-Robin syndrome and other conditions (prematurity, "near-miss-SIDS," achondroplasia, Down syndrome, et al)

4) To look for long term abnormalities in neuro-behavioral development of infants who have suffered episodes of prolonged breathing arrest, to study effects on families of home monitoring to prevent SIDS, and to explore links between infant breathing control problems and prenatal exposure to alcohol, nicotine, caffeine and other drugs.

Debra Bendell, Ph.D.
Department of Psychology and Behavioral Sciences
University of Oklahoma Health Sciences Center
Oklahoma City, Oklahoma

5) To complete follow up examination of children who have experienced new born crises such as asphyxia and brain bleeding, and were evaluated for possible predictors of SIDS, developmental delays and other adverse long term outcomes.

Lewis T. Lipsitt, Ph.D.
Department of Psychology
Brown University
Providence, Rhode Island

NATIONAL CENTER FOR THE PREVENTION OF SIDS: **SIDS-related Research**

1) Initiation of a national medical examiners' network for the purpose of collecting ideal control cases (e.g., accidental deaths of normal infants) for use in SIDS research studies everywhere. Because this material is almost impossible to obtain in numbers sufficient for statistically significant results, it is every researcher's problem.

Alfred Steinschneider, M.D.
American SIDS Institute
Atlanta, Georgia

RESEARCH APPROVED & FUNDED BY THE NATIONAL SIDS FOUNDATION

1) SIDS Recurrence Risk Estimation

Donald Peterson, M.D. 1983 ff
School of Public Health
University of Washington
Seattle, Washington

2) A Quantitative Morphologic & Neurochemical Study of the Brainstem in SIDS

Hannah Kinney, M.D. 1984 ff
Department of Neurosciences
Children's Hospital Medical Center
Boston, Massachusetts

3) Can Brainstem Deficits Explain Risk for SIDS?

Joan Hodgman, M.D. 1984 ff
Toke Hoppenbrouwers, Ph.D.
Los Angeles County/USC Medical Center
Los Angeles, California 90033

4) Investigation of SIDS: Analysis of Brainstem Lipids, Lipid Specific Enzymes & Their Relationship to SIDS

William T. Lowry, Ph.D. 1984 ff
Southwestern Medical School
University of Texas
Dallas, Texas

5) Surfactant & the Possibility of its Relationship to the Pathogenesis of SIDS

T. Allen Merritt, M.D. 1984 ff
Division of Neonatal Medicine
University Hospital
University of California at San Diego
San Diego, California

6) Role of Endorphin in SIDS

Dennis W. Neilson, M.D. 1983 ff
James K. Wamsley, Ph.D.
John Wallace Graham, M.D.
College of Medicine
Medical Center
University of Utah
Salt Lake City, Utah

Research Approved & Funded by the National SIDS Foundation

7) Further Investigation of the Physiological Significance of the Increased Tissue Lead Levels Found in SIDS & Comparison of the Epidemiology of *in utero* Lead Exposure to the Epidemiology of SIDS

Laura L. Hillman, M.D. 1982 ff
Marilyn M. Erickson, Ph.D.
Division of Neonatology
Department of Pediatrics
Washington University School of Medicine
St. Louis, Missouri

8) Assessment of the Value of Longitudinal Brainstem Auditory Evoked Potentials in Identifying Infants at Risk for SIDS & in Monitoring Those Identified as Being at High Risk

James J. Stockard, M.D., Ph.D. 1982 ff
Doris A. Trauner, M.D.
Ronald Coen, M.D.
Departments of Neurosciences & Pediatrics
School of Medicine
University of California at San Diego
San Diego, California

9) Endorphins & the Regulation of Respiration

Immanuela Moss, M.D. 1981 ff
Pediatric Pulmonary Division
Albert Einstein College of Medicine
Yeshiva University
Bronx, New York

Mr. GARCIA. Thank you very much, Dr. Dapena.

We have been joined by Mr. Monson of Utah.

Dr. Mandell.

STATEMENT OF FREDERICK MANDELL, M.D., CLINICAL ASSOCIATE PROFESSOR OF PEDIATRICS, HARVARD UNIVERSITY, VICE CHAIRMAN, NATIONAL SIDS FOUNDATION

Dr. MANDELL. Thank you, Mr. Chairman. I am Frederick Mandell. I am a children's doctor. I am the vice chairman of the National Sudden Infant Death Syndrome Foundation and I am an associate clinical professor of pediatrics at Harvard Medical School. Over the course of the last some years I guess I have met with about 5–600 families, all having lost children to sudden infant death syndrome.

I think I would like to tell you that in October of 1974 a physician was asked to address a small group of parents whose children died suddenly and unexpectedly. The physician that night understood the anguish of young parents whose lives were shattered by the tragic sudden loss of their infants. He learned that the medical community cared very little about the fate of these families, that they were left to fend for themselves after the most tragic loss of their existence, and because of that there was a special loneliness about these parents.

He learned of the taboo about talking about infants who die. He learned of accusations by family and friends, that in some way these parents were to blame for the child's death. That physician learned that in spite of the progressing technology, there was still a mystique, a shrouding of the sudden infant death syndrome.

This is what the physician learned, but what he heard were echos from young parents, young fathers and mothers, echos just like the echos of your children, Mr. Chairman, echos which called out "Why did my baby die? Why did my baby die?"

That physician was me. I have subsequently learned why the sudden infant death syndrome is unique in the spectrum of pediatric disease. It is so because of the devastation of family, of professional availability, and of self. There are siblings whose big brother or big sister roles are suddenly terminated by the death of their new family member. Children do not know that other children can die. The role of the older sibling is lost and there is a void of developmental opportunity.

There are new fathers who have accommodated to the experience of fatherhood, reshaping their world and altering the images of themselves, their wives and their children. Between the father and the child there transpired communication from the deepest parts of both participants. The crisis evoked by the effects of the sudden, unexpected shattering of that linkage between fathers and infants is profound.

Physicians themselves—and I am sure Dr. Rowland knows—report that this kind of unexpected loss is soul-searching, with feelings of self doubt, of guilt. They report that their responses to family are often intertwined with fear of blame, with fear of their own intellectual inability to provide for themselves an adequate explanation.

There are few events that so touch the heart as the passing of an infant in our practice. For pediatric health professionals, death is not a visible part of routine practice. In spite of the necessity for competence and sensitivity during this tragic experience, formal preparation for this kind of support is nonexistent. Caring physicians are saddened, stunned, and sometimes perplexed, and yet almost all are still without educational preparation.

For parents who have lost a child, the decision to have another is difficult. It is this death that has the greatest influence on the new child. Parents are deeply plagued by the possibility of losing another child. Parents require special care as they compare pregnancies, deliveries, and environments. When a child is born, the subsequent child is instantly compared with and lives in the shadow of the dead child.

These distinct conditions test the sensitivities and perceptions of the health professional. The supportive role of understanding human beings—be it parents or professionals—help mitigate the emotions of family pain and the anguish of a child dying.

The long-term effects of this wrenching and traumatic experience are not known. A father once asked, "What happens to the parent when he is no longer able to hold a child in his arms and see her smile?"

For me to have to appear here is both a happy and a sad occasion. I am happy to represent the National Sudden Infant Death Syndrome Foundation, courageous parents, and my professional colleagues. I am sad to have to continue to seek the vital and necessary support for families, for professionals, for research. I am also sad to have to continue to speak about the Sudden Infant Death Syndrome.

You see, when I walk into a meeting today, I still hear the echo. But the echo comes from meetings in every part of this country, from every lifestyle, and from the closeness of every culture. The echo is, "Why did my baby die? Why did my baby die?"

Thank you.

Mr. GARCIA. Dr. Catz.

STATEMENT OF CHARLOTTE S. CATZ, M.D., CHIEF, PREGNANCY AND PERINATOLOGY BRANCH, CENTER FOR RESEARCH FOR MOTHERS AND CHILDREN, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVEOPMENT, NATIONAL INSTITUTES OF HEALTH

Dr. CATZ. Mr. Chairman, I am Dr. Charlotte Catz, and I am the Chief of the Pregnancy and Perinatology Branch at the National Institutes of Health. I am accompanied by Miss Geraldine Norris, who is the Director of the National SIDS Program of the Division of Maternal and Child Health at the Health Resources and Services Administration.

Mr. GARCIA. If you would excuse me, Dr. Catz, I would just like to let everybody know that Congressman Alan Wheat of Missouri has joined us as well.

Dr. CATZ. I have submitted pretty long testimony but I will not go through it. It's for the record. I will try to summarize and highlight some of the aspects of the program of research that the Federal Government supports.

Mr. GARCIA. What we will do, Dr. Catz, is take your written testimony and enter it in its entirety into the record.

Dr. CATZ. Thank you.

Well, there is a historical component which we thought would be of interest, but what I want to highlight is that the NICHD program objectives are the following: we want to expand the base of knowledge of the SIDS and we want to understand the causes underlying the mechanisms of the syndrome. We want to identify infants who are at risk of becoming victims, and we want to explore, if any, preventive approaches that can be taken. We want to ascertain, by the epidemiological characteristics of that child, not only before but also after birth, to clarify the relationship between high risk pregnancy, high risk infancy in SIDS. We want to search for SIDS-specific lesions and we want to elucidate, as everybody has highlighted at this table, the impact of the sudden and unexpected death not only on the parents and the siblings and extended family, but also on others in the community.

Dr. Valdes-Dapena has summarized some of the important findings of the very large epidemiological study that we have supported. The only thing I want to highlight are certain characteristics of that child.

We know the peak incidence is betweeen the second and fourth months of life. We know that deaths occurs mainly during winter months, although as a group they are not exclusive; that nearly 60 percent of all SIDS deaths involve male infants, independent of race; that overall, they are low birth weight infants; that the materrial age, as was highlighted before, is important, occurring more in teenage mothers; that black infants are nearly three times as likely as nonblack infants to be a SIDS victim. That is the only ethnic difference that we have found. Hispanics, Asians, and whites are all within the same incidence of SIDS. That is an important consideration.

The education of the mother is also important, as has been mentioned, the smoking, the care that they received. One of the good news, if we can talk about good news, is the fact that the relationship that was thought that existed between a routine vaccination for the child and the occurrence of SIDS did not hold true once that completed study was evaluated. That is important.

One of the fallbacks of that big important study, the epidemiological study, was that there is a pathologic atlas that is being developed that will be of great use around the country for the proper diagnosis of the problem. An archive of tissues of SIDS victims has also been established and can be used by any researcher around the world for any idea that they might have in that respect.

The positive things that Dr. Valdes-Dapena has presented are real, they are there. We also work under very difficult conditions in the sense that we have to rule out—instead of studying a disease, we start with an event. We don't start with a sick child that we can identify. We have looked at infection. Now, for instance, we know that a small number of those children had infant botulism which wasn't known before. It's a small number, but it's a small number on which we can put some pride that the study had been done and it's continuing.

We had also looked at the physiology of that child in order to understand what happens. Obviously, the child that is born can breathe, have a heart function, can eat, can sleep and can coordinate that. But how do they do it? We have learned a lot through the program of high risk infancy about the normal development of those children which is fundamental and of high priority to understand what might be abnormal.

The relationship between apnea—that is, the cessation of breathing—during small periods of time which might or might not be related to SIDS still has to be determined. But it is an important area of study that is continuing today.

We know that some of the studies have necessarily had to look at the infants that are considered at risk, which are siblings of SIDS victims already, children that we have identified at high risk for the epidemiological study. That is the importance of that study, to give us leads into where to direct our research.

There has been a lot of talk about monitors, and we are planning what we call a consensus development conference for September of 1986, in which a panel of participants who are already starting to work now will examine all of the available data and not only try to make some sense about what the meaning of that data is, but also lead into what are the next questions that have to be examined and supported.

As I said, we know that all these functions have to be synchronized. Dr. Valdes-Dapena has mentioned that we actually are moving into the direction of neurosciences. We know of the pathology found in the brainstem. There is another researcher that we are supporting in animal models in which small amounts of decreased oxygen availability was reduced and found the acidity or alkalinity surrounding the brainstem was different. This is a very important lead that is being pursued quite actively. So we are looking at the central nervous system and we are really issuing very soon—it's ready to be issued—a request for applications to stimulate good researchers in the neurosciences to start thinking about sudden infant death and not necessarily on other aspects of neurosciences that are as important but could not deny this importance.

So we do feel that there is a certain immaturity, quote-unquote, whatever that term means, in regard to the health of that infant, and that all the research that the National Institutes of Health is supporting in regard to high risk infancy and high risk pregnancy—although it has been designated by Congress in the amendment act of 1974—has generally related to SIDS, but actually they are very directed to SIDS, directly related to SIDS, although they are not classified as such. Therefore, when mention has been made that there is a decrease in funds available for directly related research to SIDS, we really have to consider the whole amount that is being put into those different aspects. If we look at the bottom line from 1980 to now, there has been a constant and even a progressively slight increase of funds, around $17 million a year.

Now, obviously it has been said at this table that the problem is not only the medical-physiological aspects but the tragedy of the

SIDS deaths have been well explained and I don't have to go int it.

In order to help the families of victims to understand SIDS and cope with their feelings about the deaths, and to assist the professionals, the SIDS Act of 1974 directed the Division of Maternal and Child Health of the Health Resources and Services Administration to support the SIDS Counseling and Information Program. The services provided by this program were consolidated in 1981 in the Maternal and Child Health [MCH] block grant. Each State assumed the responsibility to develop its own MCH Program, establishing priorities and allocating funds accordingly.

So far, almost every State reports using a portion of its block grant to provide SIDS-related services. There is also support of research that is related to services and those other aspects that related to education. There is, for instance, by the American SIDS Institute in Atlanta, GA, a program to evaluate the significance of certain signs which may identify intants at risk for episodes either of prolonged apnea, or a slowing down of the heart rate, or bradycardia, and they are studying the siblings of SIDS victims. This is over a 6-month period that those infants are studied very carefully. They also have prepared a guideline that is based on available research findings regarding the clinical management of infants who are at increased risk for SIDS.

There are investigations in other universities looking at the impact of the loss of a child and how can one predict how parents can successfully adapt to such a terrible loss.

There is a demonstration program in West Virginia which is establishing a statewide system to identify infants who need closer scrutiny and link them to apropriate services. This will answer questions about clinical management of these high-risk infants.

There is also a contract that supports a National SIDS Clearinghouse which provides information and educational materials to everybody that needs it. So we do have all those things, and plans are in progress for a National SIDS conference, also to be held in September of 1986, which will be a national forum for exchange of information, not only between the public and private organizations but also with families and everybody involved with SIDS research.

So we have this broad array of research, demonstration, service and information activities of the Public Health Service which is focused really on the elimination of SIDS and the pain that it inflicts.

In addition to the NICHD there are other NIH institutes that are involved—the Food and Drug Administration, the Centers for Disease Control, the National Center for Health Statistics, the Administration for Children, Youth and Families, and groups such as the American Academy of Pediatrics, the National Sudden Infant Death Syndrome Foundation, the Guild for Infant Survival, and the National Center for the Prevention of SIDS. Working with the Congress, and public and private agencies at all levels, we will continue this effort until we are successful.

Ms. Norris and I can answer any questions that the members may have.

[The statement of Dr. Catz follows; also included are the responses to written questions:]

TO BE RELEASED UPON DELIVERY ONLY

STATEMENT BY

CHARLOTTE S. CATZ, M.D., CHIEF

PREGNANCY AND PERINATOLOGY BRANCH

CENTER FOR RESEARCH FOR MOTHERS AND CHILDREN

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

NATIONAL INSTITUTES OF HEALTH

ON

SUDDEN INFANT DEATH SYNDROME

BEFORE THE

SUBCOMMITTEE ON CENSUS AND POPULATION

OF THE COMMITTEE ON POST OFFICE AND CIVIL SERVICE

THE SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES

AND THE

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

OF THE COMMITTEE ON ENERGY AND COMMERCE

U.S. HOUSE OF REPRESENTATIVES

NOVEMBER 14, 1985

Mr. Chairman and Members of the Subcommittees and Select Committee:

I am pleased to be here today to provide information on the SIDS-related activities of the Public Health Service. I am Dr. Charlotte S. Catz, Chief of the Pregnancy and Perinatology Branch, National Institute of Child Health and Human Development, NIH, which has the responsibility for Federal SIDS research. I am accompanied by Ms. Geraldine J. Norris, Director of the National SIDS Program, Division of Maternal and Child Health, HRSA.

National Institutes of Health Activities

The National Institute of Child Health and Human Development (NICHD) is the primary focus at the National Institutes of Health (NIH) for research on maternal and child health. The main objective of research supported by the NICHD is to ensure the birth of healthy babies and their optimal development so that they can enjoy a productive and healthy adulthood. Sudden infant death tragically ends this normal progression.

Each year, an estimated 7,000 infants in the United States become the victim of crib death or SIDS (Sudden Infant Death Syndrome), as it is called today.

The sudden, unexplained death of a baby is not a 20th century phenomenon. Gravestone inscriptions during the Middle Ages referred to such deaths. So did the Bible 2,000 years ago in the passage "...and this woman's child died in the night because she overlaid it."

The erroneous assumption of "overlaying" or smothering of the baby by a sleeping parent lasted well into the 19th century. Then, in 1892, an excellent paper describing the phenomenon of SIDS appeared in the Edinburgh Medical Journal. However, it was not until the 1940's that systematic studies of the problem began. SIDS received a boost as an object of research after the NICHD held two international conferences on the subject in 1963 and 1969.

In the early 1970's, the U.S. Congress held its first hearings on the problem. This interest led to the passage in 1974 of the "Sudden Infant Death Syndrome Act of 1974" (P.L. 93-270), giving to the NICHD the mandate to lead the Federal effort in SIDS research and to the Division of Maternal and Child Health the responsibility for the SIDS Counseling and Information Program.

The scientists participating in the early NICHD SIDS conferences agreed on two fundamental statements. At the 1963 conference, the scientists agreed that the age of death (between 2 and 3 months) might be a transitional period when infant responses may change from neonatal to more mature ones. At the 1969 conference, they achieved a consensus regarding an official definition of SIDS, a definition which continues to be used today: "The sudden death of any infant or young child, which is unexpected by history, and in which a thorough postmortem examination fails to demonstrate an adequate cause of death." This definition has been extremely useful by focusing the attention on cases where obvious factors contributing to death are absent.

The NICHD program objectives have been and continue to be to expand the base of knowledge about the Sudden Infant Death Syndrome: specifically to understand the causes and underlying mechanisms of the syndrome; to identify infants at risk for becoming victims; to explore preventive approaches; to ascertain the epidemiologic characteristics of the SIDS victim, the SIDS family, and the victim's environment, both before and after birth; to clarify the relationship between high-risk pregnancy, high-risk infancy and SIDS; to search for SIDS-specific lesions; and to elucidate the impact of a sudden and unexpected infant death on parents, siblings, the extended family, and others.

The NICHD has had a long-standing interest in the epidemiology of SIDS in the hope that through understanding the characteristics of the "typical" SIDS victim and of the environment surrounding that infant, a common set of factors may emerge that will help us to better understand SIDS and to identify its potential victims.

During the past year, additional results of the NICHD Cooperative Epidemiological Study of SIDS Risk Factors — the largest epidemiological study of SIDS ever undertaken — were analyzed. The data provide the scientific world with an extensive, multidimensional profile of SIDS in America.

By interviewing the families of 800 SIDS victims and of some 1600 live control infants, researchers were able to gather a wealth of data on family characteristics such as socioeconomic status, and parental age, health and education, as well as on the infant's own health, birth, and eating and sleeping habits. From detailed comparisons between the families with and without infants who died of SIDS, the following SIDS profile emerged:

1. Age and Other Characteristics: Ninety percent of the SIDS deaths occurred before the child was six months old; 98 percent died before their first birthday. The peak incidence was found to be between the second and fourth months of age. Most victims died at home in their cribs. The frequency of SIDS deaths was greatest during the cold weather months. It was also higher between 12 midnight and 8 a.m. than during other hours of the day. In the majority of cases, the SIDS baby was reported to be well nourished, well developed and in good health before death. Multiple birth was found to produce an increased risk of SIDS: Such infants were 2 1/2 times more likely to die of SIDS.

2. Sex: Nearly 60 percent of all SIDS deaths involved male infants, regardless of race.

3. Birthweight: Overall, 24 percent of the infants who died from

SIDS were low birth weight (weighed less than 5 1/2 pounds at birth). Only 6.5 percent of the living controls were low birth weight.

4. Maternal Age and Birth Order: Overall, 32 percent of the SIDS infants were born to teenage mothers, compared to about 19 percent of control infants. Second or subsequent infants were found to be at a higher risk for SIDS than first-born children, regardless of the mother's age.

5. Race: Black infants are nearly three times as likely as non-black infants to be a SIDS victim.

6. Education: Approximately 57 percent of the mothers of SIDS infants had not completed high school; in the control group, only 35 percent of the mothers had not finished high school.

7. Maternal Smoking in Pregnancy: Approximately 70 percent of the mothers of SIDS infants smoked during their pregnancy, compared to about 40 percent of the mothers of the control infants.

8. Pediatric Care: SIDS infants were less likely to have had regular pediatric checkups compared to the control infants. However, there were no significant differences in the proportion of infants who made visits to the pediatrician because of illness among infants who died of SIDS and those who did not.

9. Vaccination for Polio and Diphtheria/Pertussis/Tetanus (DPT): SIDS infants were more likely not to have received either polio or DPT vaccinations. This study clearly refuted earlier suggestions that there is a correlation between receiving DPT vaccinations and SIDS.

In addition to providing researchers, physicians, and families with a detailed profile of the SIDS infant, the NICHD Cooperative Study of SIDS Risk Factors is generating the production of a comprehensive SIDS Histopathology

Atlas. Since most pathologists do not see many SIDS cases during their career, this atlas will be a valuable resource to help them differentiate between SIDS and non-SIDS cases.

Also, an archive of preserved SIDS pathology tissues has been prepared with NICHD support by the Medical Examiner's Office in San Francisco. The Armed Forces Institute of Pathology has agreed to house this tissue archive. This archive is available to scientists around the world to use in their research. The availability of this unique resource is expected to encourage and facilitate research on SIDS.

Biomedical research has been successful in ruling out several suspected causes of SIDS, such as accidental suffocation, malnutrition or parental neglect, inhalation of formula after spitting up, allergy to cow's milk, or the common cold or influenza. It has not yet, however, been able to identify the specific cause or causes of crib death, nor has it been able to accurately predict which specific infants may die of SIDS.

Researchers have also looked at the possible role of infection in SIDS death. NICHD-supported scientists have been studying infectious agents that grow in the intestinal tract and have been suspected of causing SIDS. In infant botulism, ingested spores of the bacterium Clostridium botulinum multiply and produce their toxin in the baby's intestine, which lacks the adult's ability to fight infection. Once absorbed, the toxin reaches motor nerve endings and paralyzes respiratory muscles, resulting in death. Although the investigators doing this work ultimately concluded that only a small percentage of SIDS deaths could be attributed to this agent, this work, in addition to expanding our knowledge of factors that influence toxin absorption in infants, did lead to a procedure by which the time needed to diagnose infant botulism has been cut from four to two days.

Much of the NICHD SIDS research program focuses on clarifying the specific physiologic changes which may be of importance in understanding SIDS events. To this end, the NICHD set up a wide-ranging program to generate base-line information on respiratory, cardiac, and neurophysiological parameters in normal infants.

One area that has received much research attention is the possible role of sleep apnea in SIDS. Earlier studies examined the role of sleep apnea (cessation of breathing for at least 20 seconds or a briefer episode associated with slowed heart rate, bluish discoloration, or pallor, and requiring resuscitation) as an antecedent to death.

To clarify the relationship, if any, between apnea and SIDS, studies are delineating the normal development of the respiratory control center in the brain. One group of studies carried out in normal infants and in siblings of SIDS victims who are at increased risk for SIDS, showed that high-risk infants took longer to arouse from sleep when changes in their environment (minor decreases in available oxygen) were instituted.

This research reinforces earlier data indicating that children at risk for SIDS — i.e., siblings of SIDS victims, premature babies, babies of teenage mothers, and infants who have frequent and/or prolonged episodes of apnea — show disturbed brain wave activity and different sleep patterns from other infants. NICHD-supported research has contributed to the development of an improved neonatal apnea monitor. This monitor, in addition to sounding an alarm, records the cause of the alarm signal, including readings of abnormal heart rate and breathing functions.

The NICHD plans a consensus development conference for September 29, 30 and October 1 of 1986 on "Infantile Apnea and Home Monitoring." The participants will try to reach a consensus on what is known about the relation of neonatal and infant apnea to each other and to mortality (especially SIDS) and morbidity in infancy; the effectiveness and safety of currently available home devices for detecting infant apnea; and what evidence there is that home monitoring is effective in preventing repeated episodes of apnea and, perhaps, SIDS. The Institute hopes that recommendations regarding the circumstances for the use of home apnea monitoring in infancy will be clarified based on findings from this conference. In addition, further research needed on home monitoring for infant apnea will be identified.

Although apnea or other defects in respiration have long been suspected of being implicated in SIDS, no specific link has been found. Recently, research emphasis has shifted from looking for specific defects in the control of breathing toward the investigation of prenatal development of the central nervous system. Researchers are specifically exploring how early central nervous system development relates to maturation of circulatory, respiratory, and neurologic functions. Synchronized maturation is necessary for the infant's adaptation and survival in the environment outside of the womb.

Results to-date include evidence of correlations between clinical and morphological data that point to dysfunction of respiratory control as a possible major cause of SIDS. Pathology studies have shown tissue alterations in the lungs and the central nervous system, particularly the brainstem of SIDS victims. Other studies have confirmed the role of the brainstem in the neurological activation of respiration, the modulation of breathing, and in arousal from sleep. Researchers are accumulating evidence based on several animal models that SIDS victims have defects in one or more of these functions. In addition, changes noted in tissues from animal studies are consistent with those observed in human SIDS victims. This consistency further strengthens the theory that SIDS is caused by a combination of deficiences of certain functions in the infant leading to its failure to adapt to life outside of the womb.

Continued research is needed to further substantiate this theory and to pinpoint the specific immaturities that are implicated in SIDS. A Request for Grant Applications targeted at SIDS is now ready for release for funding during this fiscal year. We are particularly interested in stimulating SIDS research related to central nervous system development and maturation. It is our hope that we will receive applications for research to follow up some of the promising leads now available, and that findings from some of our previous studies will spark a new idea or theory for scientists to investigate in order to find the cause or causes of SIDS and to prevent this tragic mystery.

Health Resources and Services Administration Activities

Often compounding the tragedy of a SIDS death are the grief and resulting feelings of guilt, frustration, and the compelling need to understand "Why?". In addition, the families of SIDS victims are sometimes the targets of misunderstanding and accusations.

In order to help the families of victims to understand SIDS and to cope with their feelings about the deaths, and to assist professionals in helping families as they resolve their grief, the SIDS Act of 1974 directed the Division of Maternal and Child Health of the Health Resources and Services Administration (HRSA) to support a SIDS Counseling and Information Program. The services provided by this Program were consolidated in FY 1981 within the Maternal and Child Health (MCH) Block Grant. Each state assumed the responsibility to develop its own MCH program, establishing priorities and allocating funds accordingly. Almost every state reports using a portion of its block grant to provide SIDS-related services mainly for the classification of unexpected infant deaths; the certification of the cause of death by autopsy and other death investigation methods; the prompt notification of the family of autopsy findings; and the provision of counseling and information for families. Some efforts are directed towards public information and professional education, collection and analysis of data, and community participation through advisory councils.

The MCH Block Grant Program authorizes a set-aside program for projects of regional and national significance which are administered by the Division of MCH in HRSA. The findings or products resulting from research, demonstration projects, and service activities may, in turn, be adapted by the states to improve the health status of SIDS victim families through improved services.

An ongoing research project conducted by the American SIDS Institute in Atlanta, Georgia is evaluating the significance of certain signs which may identify infants at risk for episodes of prolonged apnea or bradycardia (slowed heart rate). Infants born to families who have suffered a previous SIDS loss are being tested. The study will determine the value of measurements of respiratory instability obtained during feeding and sleep, and will assess passive muscle tone during the first and fourth week of life. These infants will be monitored at home for a period of six months to obtain accurate documentation of each episode of prolonged apnea or bradycardia. At the request of the Division of MCH, the American SIDS Institute also recently provided a set of guidelines, based on available research findings, for the clinical management of infants at increased risk for SIDS.

Investigators at the University of Michigan are seeking to determine the psychosocial impact of the loss of an infant to SIDS, and to identify the predictors of successful adjustments to such a loss. Better understanding of these parameters will improve interactions with SIDS parents, and facilitate providing assistance appropriate to their specific psychological needs.

A demonstration program in West Virginia is establishing a state-wide system to identify infants who need closer scrutiny and link them to appropriate services. This program will also gather prospective data to help improve surveillance, patient evaluations, follow-up, and parental support, particularly for teenage mothers. This coordinated, multifaceted program will answer questions about the clinical management of these high risk infants.

A service contract is supporting the National SIDS Clearinghouse which was established in 1980 to provide information and educational materials on SIDS to health care professionals, community service personnel, SIDS parents, and the general public. Services provided by the SIDS Clearinghouse include: responding to public inquiries and making referrals to local SIDS programs and parent support groups; disseminating current fact sheets, bibliographies and referral lists; compiling an automated database of current SIDS literature and a comprehensive resource collection; and distributing the Information Exchange, a quarterly publication which is a national forum for sharing SIDS-related information.

In addition to continuing these clinical research and service demonstration projects, plans are in progress for a National SIDS Conference to be held in September of 1986. This conference will provide a national forum for the exchange of information between public and private organizations and families concerned with SIDS and its related issues.

Mr. Chairman, this broad array of research, demonstration, service, and information activities of the Public Health Service is focused on the elimination of SIDS and the pain and suffering that it inflicts. In addition to the NICHD and the Division of MCH, these activities encompass the efforts of other NIH institutes, the Food and Drug Administration, the Centers for Disease Control, the National Center for Health Statistics, the Administration for Children, Youth and Families, and groups such as the American Academy of Pediatrics, the National Sudden Infant Death Syndrome Foundation, the Guild for Infant Survival, and the National Center for the Prevention of SIDS. Working with the Congress, and public and private agencies at all levels, we shall continue this effort until we are successful.

This concludes my statement. Ms. Norris and I would be glad to answer any questions that you might have.

National Institutes of Health
Bethesda, Maryland 20205
Building :
Room :
(301) 496-

December 26, 1985

The Honorable Robert Garcia
Chairman
Subcommittee on Census and Population
Committee on Post Office and Civil Service
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Garcia:

I have enclosed the responses to the two sets of follow-up questions from the joint hearing on sudden infant death syndrome. I would be pleased to provide any additional information which may be helpful to you.

Thank you for your leadership in the effort to overcome this dread disorder.

Sincerely,

Charlotte Catz, M.D.
Chief, Pregnancy and Perinatology Branch
Center for Research for Mothers
and Children
National Institute of Child Health
and Human Development

QUESTION I., 1.

Why are teenagers more at risk to have infants who die of SIDS? Why do black infants have a higher risk of SIDS than non-black infants?

ANSWER:

The answers to both parts of this question significantly overlap. As a group, the babies of teenage mothers have a greater number of health problems such as low birthweight, which is the leading cause of all perinatal mortality. Many adolescent mothers are black, disadvantaged economically, smoke, have less schooling, and many do not receive prenatal care. Epidemiologic research has shown that all of these factors increase the risk for SIDS. Therefore, both groups — teenage mothers and black mothers — present a greater concentration of known risk factors for SIDS. It is important to recognize that research efforts addressing issues in high-risk pregnancy, high-risk infancy, low birthweight, prematurity, adolescent pregnancies, and the development of risk-taking behaviors all contribute to the knowledge needed to understand the role these factors, either individually or conjointly, play in the causation of SIDS.

QUESTION I., 2.

Can you explain the significant decrease in money allocated to SIDS specific research? Is more money needed?

ANSWER:

The number of grants approved and dollars expended in SIDS specific research since 1981 have indeed decreased, but this fact needs to be interpreted in terms of program activities. One factor in the decline in SIDS specific research funding between 1981 and 1984 was the completion during this period of the NICHD Cooperative Epidemiologic Study of SIDS Risk Factors, the largest epidemiologic study of SIDS ever conducted. This multi-center study funded by contracts accounted for a substantial part of the SIDS specific funding from 1979 to 1982. The subsequent completion of the initial analyses of that study, combined with a SIDS research planning workshop the NICHD held last year, provided new leads for the scientific community to pursue. This is reflected both in the increase in SIDS specific funding in FY 1985 to $1.074 million, and the issuance of a Request for Grant Applications (RFA) on SIDS by the NICHD in FY 1986 to stimulate submission of more research proposals.

The figures on SIDS research are not reported only as a single number (total SIDS) but also as SIDS specific and SIDS general, the latter encompassing projects in High-Risk Pregnancy and High-Risk Infancy research areas. The subdivision into specific and general, mandated by the SIDS Amendments of

1979 (P.L. 96-142), gives recognition to the close relationship between SIDS and high-risk states associated with pregnancy and/or infancy. SIDS specific grants are limited to those which address issues already identified as directly related either to mechanisms responsible for SIDS, or to various aspects of the SIDS victim, SIDS siblings and/or parents.

The total SIDS budget figures from 1980 to 1984 have not shown a decrease in support but a constancy and, since 1982, a slow but steady tendency toward higher expenditures. The amounts are: FY 1980 - $16,896,000; FY 1981 - $18,766,000; FY 1982 - $16,465,000; FY 1983 - $16,572,000; and FY 1984 - $17,184,000. The preliminary figure for 1985 is $17,845,000.

The quantity and quality of applications received vary and explain the observed fluctuations in funding. The present budget can accommodate current proposals, and the NICHD SIDS program has not been limited by the availability of funds.

QUESTION I., 3.

Are you currently supporting SIDS-related activities through SPRANS (Special Projects of Regional and National Significance)?

ANSWER:

Yes, the Division of Maternal and Child Health (DMCH) currently is supporting SIDS-related activities through SPRANS. During Fiscal Year 1985, the following activities were supported by DMCH:

Research Grants

1. Project: Identification of Risk for Siblings of SIDS Victims
Director: Alfred Steinschneider, M.D., Ph.D.
State: Georgia
Amount: $111,432

2. Project: SIDS Loss: Psychosocial Impact and Predictors of Coping
Director: Camille Wortman, Ph.D.
State: Michigan
Amount: $114,082

Demonstration Grants

1. Project: West Virginia State-wide SIDS Program
Director: David Myerberg, M.D.
State: West Virginia
Amount: $177,880

2. Project: Model Intervention for Survivors of Sudden Death of Children: Prevention of Abnormal Grief
Directors: John Smialek, M.D. & Beverly White, R.N.,M.S.
State: New Mexico
Amount: $113,322

Contracts

1. Project: National SIDS Clearinghouse
Director: Janice Berger
State: Virginia
Amount: $147,288

2. Project: SIDS Advisory Panel
Director: None
State: None
Amount: $ 5,259

3. Project: SIDS Planning Group for National Conference in 1986
Director: None
State: None
Amount: $ 3,086

TOTAL $672,349

QUESTION I., 4.

Is research on SIDS a priority at the National Institute of Child Health and Human Development?

ANSWER:

Yes, SIDS research has been for many years, and continues to be, a priority at the National Institute of Child Health and Human Development (NICHD). The NICHD SIDS research program began with the founding of the Institute in 1963. From a modest beginning, the program grew by 1974 into a major priority research program. This is evidenced by the fact that the percentage of approved grants and contracts which are funded in the area of SIDS has consistently exceeded the percentage for the Institute overall.

QUESTION I., 5.

One of the witnesses criticized in her testimony the research at the NICHD. She states that the majority of the Institute's research dollars has gone to developing apnea monitors. Is that a correct statement?

ANSWER:

No, this is not correct. The research expenditures of the NICHD SIDS program cover a wide spectrum of interrelated areas. These include, among others, the role of infections as a cause of SIDS; the control of breathing and breathing patterns in newborns and infants at risk; the pattern of heart rate in high risk infants; the organization of sleep states; and the prenatal development of the central nervous system. Using the Small Business Innovation Research Program established by Congress, the Institute, for the first time in FY 1985, funded one project to develop an improved, low-cost, sensitive apnea monitor. This one project, which amounts to only 3% of the FY 1985 NICHD total SIDS research expenditure, is a small but important part of the effort to prevent SIDS deaths.

QUESTION I., 6.

Now that the Institute has completed its in-depth epidemiological study of SIDS risk factors, how are the findings of this study being used? Have additional studies begun as a result of the conclusions drawn from the epidemiological research?

ANSWER:

The NICHD Cooperative Epidemiological Study of SIDS Risk Factors has completed both the data collection phase and an analysis of half of the data on the 800 SIDS victims and 1,600 infant controls. The final analyses of the total data set are continuing at this time. Analysis of the first half of the data was planned in order to identify any new leads which could be more specifically pursued during the analyses of the second half of the data. Once the final analyses are finished, the results will be made available to the scientific community. A preliminary suggestion of this and other studies is that SIDS infants may be different in their central nervous system maturation. This preliminary finding points to the possibility of abnormalities in the brainstem of SIDS victims. This lead is being pursued by the NICHD through the support of a grant to systematically examine the brainstems of SIDS victims. In addition, the NICHD is issuing a Request for Grant Applications (RFA) which identifies prenatal nervous system development as a particular focus for research on SIDS.

QUESTION I., 7.

Are the causes of SIDS different for different SIDS victims?

ANSWER:

Unfortunately, the cause, or causes, of SIDS are not yet known. The evidence obtained to date indicates that SIDS may result from a variety of causes. Consequently, the NICHD supports a wide range of studies classified not only as SIDS specific but also SIDS general, which encompasses projects in High-Risk Pregnancy and High-Risk Infancy.

QUESTION I., 5.

You've mentioned in your testimony that through research SIDS infants have been found to be not as "normal" as they were once thought to be but that there are some distinctions between normal infants and SIDS infants. Would it be possible to see such distinctions in time to prevent SIDS? If so, how?

ANSWER:

The recognition that SIDS victims are not as "normal" as they were once thought to be is the result of retrospective inquiries. Parents, when asked, sometimes do recognize differences between their SIDS victim child and their other children. However, these differences in behavior, growth pattern, cry, etc., were not identified before death. Some are very subtle and fall within normal and expected variations, with no specific patterns common to all victims. It is hoped that studies will eventually prospectively identify potential victims, making it possible to prevent SIDS deaths.

QUESTION II., 1.

How much money was awarded in the NICHD research grants and contracts for SIDS primary research in each of the years 1980-1985? How much will be awarded in FY 1986?

ANSWER:

The NICHD SIDS primary research grants and contracts for the years 1980 through 1985 were funded in the following amounts: FY 1980 - $2,704,000; FY 1981 - $3,368,000; FY 1982 - $2,763,000; FY 1983 - $1,780,000; FY 1984 - $657,000; FY 1985 (preliminary) - $1,074,000. The SIDS primary amount in the President's Budget for the NICHD in FY 1986 is $1,000,000.

QUESTION II., 2.

Please list the SIDS primary research projects funded by the NICHD in FY 1985, with descriptions and amounts awarded.

ANSWER:

SUMMARIES OF SIDS PRIMARY RESEARCH PROJECTS, FY 1985

5 R01 08693 12 Infection Enhancement - An Experimental Model of SIDS
Morens, David M.
University of Hawaii at Manoa
Honolulu, Hawaii $144,215

This study deals with the possibility that enhanced infection results in enhanced disease. Specifically, it proposes to investigate the mediation of viral infection by non-neutralizing antibody. This infection of mononuclear phagocytes by dengue virus is the prototype for this phenomenon. The ultimate research goal is to identify effector mechanisms in dengue disease and to evaluate analogous immunopathological mechanisms and effectors which might be responsible for triggering sudden infant death syndrome.

5 R01 10993 07. Control of Breathing in Recovery from Apnea
Thach, Bradley T.
Washington University
University City, Missouri $124,483

This research concerns the physiologic mechanisms involved in initiation and recovery from apneic spells. Special emphasis is given for apnea associated with upper airway obstruction. The investigators plan to study mechanical and neuromuscular factors relevant to pharyngeal airway maintenance in anesthetized living and dead animals and to evaluate pharyngeal airway compliance. These studies are relevant to the maturation and development of respiratory control in man and to the clinical syndromes of Pierre Robin syndrome, apnea of prematurity, sleep obstructive apnea and sudden infant death syndrome.

2 R01 15736 04A1 Endorphins, Sleep and Maturation of Hypoxic Response
Haddad, Gabriel G.
Columbia University
New York, New York $185,168

This project deals with the role of endorphins in ventilatory and cardiovascular control at rest and during stress (e.g., hypoxia) as a function of age and state of consciousness in unanesthetized chronically instrumented young and adult animals. This research is of particular relevance to the understanding of the pathogenesis of sudden infant death syndrome. This research will provide new and important data on the relationship of the state of consciousness, cardiorespiratory control and oxygen consumption to blood and cerebrospinal fluid endorphin levels after milk feeding.

2 R44 18534 02 Low-Cost Motion-Sensitive Apnea Monitor
Walls, James A.
Biodyne $497,000
Orange, Connecticut

This project deals with the continued development of a low-cost, diaphragmatic motion-sensitive apnea monitor that is portable and easy to use. Laboratory and clinical evaluations have validated the technological feasibility for possible use in infants designated as near-miss or siblings of SIDS victims who qualify for monitoring.

1 R01 20909 01 Oscillatory Patterns of Breathing and Heart Rate in SIDS
Waggener, Thomas B.
New England Medical Center Hospital $69,981
Boston, Massachusetts

The goal of this research is to determine whether analysis of oscillatory patterns in respiration and heart rate can identify infants at risk to die of the sudden infant death syndrome. Because oscillatory patterns underlie apnea and hypoventilatory events, analysis of these patterns, rather than tabulation of numbers of apneas or percent time apneic, may identify abnormalities associated with SIDS. The analysis covers a wide range of oscillatory phenomena including the characterization of the patterns as well as the frequency of their occurrence.

5 K04 00475 04 Control of Breathing in Newborns
Lawson, Edward E.
University of North Carolina $53,443
Chapel Hill, North Carolina

The objectives of this research are (1) to demonstrate the existence of a central mechanism which mediates the transient respiratory response to hypoxia of newborns; (2) to further characterize the long-acting central inhibitory mechanism activated by superior laryngeal nerve stimulation; and (3) to study the effects of hypoxia on metabolism of central neurotransmitters related to control of breathing.

QUESTION II., 3.

How many grant applications in SIDS primary or secondary research were approved but unfunded in FY 1985? How much would it cost to fund these projects?

ANSWER:

In FY 1985 there were five approved but unfunded SIDS primary grant applications. Funding for these unfunded SIDS primary applications would total $405,474. There were 29 approved but unfunded SIDS secondary grant applications in FY 1985. The cost of funding these 29 unfunded applications would total $3,103,171. It should be noted, however, that the peer review priority scores for these applications were significantly below the Institute's payline. In other words, these applications were not judged to be of high scientific value.

QUESTION II., 4.

Given what we know about SIDS risk factors and promising research areas — especially in light of findings from the 7-year NICHD cooperative study — what are NICHD'S priorities in the award of grants and contracts over the next 5 years? What are the focus areas for research in the near future?

ANSWER:

While the NICHD will continue to pursue a number of significant leads such as the role of infections, sleep patterns and apnea, heart rate fluctuations, etc., a major developing new hypothesis is that SIDS may result from a failure not just of one organ system, but rather from a failure of the complex interplay of the regulatory systems required to maintain life. The developing brain with its specific centers is the area where the control of life-sustaining functions takes place. Future research utilizing new concepts in neuroscience will address questions regarding the pathogenesis of SIDS in the context of the role of the brainstem and other central nervous system centers in the control of vital functions. Specific areas of interest include metabolic activity of brain and central nervous system cells and tissues; functional development of the blood-brain barrier with regard to both barrier and carrier functions; development of the autonomic nervous system and its role in the regulation of vital functions; and the potential role of circadian rhythms endogenously generated by a multiple oscillator system and their relationship to SIDS. An additional research objective is to develop an experimental animal model for SIDS.

As with all biomedical research, these emphases are likely to shift as new knowledge is developed. The NICHD is pursuing these objectives now, and will continue to do so until breakthroughs are achieved or better opportunities are discovered.

QUESTION II., 5

Aside from the NICHD grants and contracts, what other sources are there, within the federal government or private sector, for SIDS primary research?

ANSWER:

In the Public Health Service, virtually all SIDS primary research is supported by the NICHD and the Division of Maternal and Child Health (DMCH) of the Health Resources and Services Administration. In the private sector several groups also seek to provide support for SIDS primary research. These include the National Sudden Infant Death Syndrome Foundation, the Guild for Infant Survival, and the National Center for the Prevention of SIDS.

QUESTION II., 6

Of the research projects on high-risk pregnancy and high-risk infancy (and other "basic" research) currently funded by the NICHD, are there any with specific and demonstrable implications for SIDS research?

ANSWER:

Until the cause or causes of SIDS are specifically identified, it is not possible to precisely identify grants with specific implications for SIDS among those addressing various issues within the high-risk pregnancy and high-risk infancy categories. Based on our current knowledge, however, it is obvious that it would be beneficial to SIDS research to clarify the specific role of the placenta for the well-being of the fetus, the role of various maternal conditions and treatments in regard to fetal development and maturation, as well as to gain an understanding of the determinants and consequences of low birth weight, which are the objectives of many grants in the high-risk pregnancy category. Similarly, SIDS research is likely to be advanced by improving our knowledge in areas of disorders of the newborn such as infant infections, metabolic capabilities, functional development of various organ systems including the central nervous system, the developing capabilities to adapt to a new environment, and the ability to handle medications, which are among the objectives of high-risk infancy research. These subjects are all pertinent to our understanding of developing fetuses and growing infants and the existence of various mechanisms to respond to multiple stresses in their surroundings. The development of new knowledge in these areas of research is very likely to directly advance our quest to conquer SIDS.

Mr. GARCIA. Thank you very much, Dr. Catz. I guess you're working together as a team now.

Just let me say that we have been joined by my colleague from New York, Congressman Ted Weiss.

What I am going to do is open it up to questions at this point, but I will not ask questions. As a credit to all of you, I would like you to know I am deeply appreciative because so many Members of Congress from all different sections and parts of the country have responded to this hearing today. So I think it is a tribute to Congress wanting to know more about SIDS.

I am going to start off with my colleague from California, Mr. Miller.

Mr. MILLER. Thank you.

Dr. Catz, how do we know what the States are doing now? I mean, how do we find out this information?

Dr. CATZ. I will have to ask Ms. Norris, who is in charge——

Mr. MILLER. We used to have reporting requirements, is that correct?

Ms. NORRIS. Yes. When the legislation was passed in 1974, data collection was included as one of the requirements. Since the program has gone into block grants, the Association of State and Territorial Health Officers has been collecting some data on sudden infant death syndrome. It's a voluntary reporting system.

Mr. MILLER. Is it complete for all the States?

Ms. NORRIS. About 43 States reported information last year. It had to do with the number of suspected cases of SIDS in States, the number of autopsies done, and the number of families counseled. Not all States obviously reported.

Mr. MILLER. But it didn't cover of what their expenditures might be on aspects other than family counseling?

Ms. NORRIS. No. There was a GAO report completed in 1984, and then we did an evaluation of the impact of block grants on SIDS in 1983. Both of those reports indicated that once the programs were integrated into the larger maternal and child health program it was difficult for States to inform us exactly what amounts of funds had been expended on the SIDS program.

Mr. MILLER. So we don't really know.

Ms. NORRIS. That's correct.

Mr. MILLER. Dr. Valdes-Dapena, you mentioned in your testimony that research would be required to develop pediatricians' diagnostic capabilities and to develop a plan for SIDS prevention, which I assume is related to adequate maternal health, and for further investigation of the infant central nervous system.

What is going on at NICHD to support these efforts? You mentioned one grant was cut in half.

Dr. VALDES-DAPENA. One grant was approved in October. The application was for $300,000 for each of 3 years. It was funded at the rate of half of that. I don't know what impact that cut of 50 percent will have on that program. It was undoubtedly the best of its kind.

I am not familiar with other neuroscience studies, except another one going on in that same laboratory. But that is the quality and the kind of research that has got to get underway.

Mr. MILLER. Let me ask you, with respect to the maternal health issues, what happens to the mothers prior to the birth of these children? Is there a Federal plan being developed to deal with this?

Dr. VALDES-DAPENA. In a sense, the general funds that Dr. Catz referred to are touching on those very issues, the impact of low birth weight, prematurity, smoking effects. In fact, that is tangential to the question. Those studies will have some impact. They are not directed to SIDS but they're general and they touch on it.

Mr. MILLER. On the theory that if you improve the general health of this population——

Dr. VALDES-DAPENA. It probably, in some vague ways that we don't understand, is going to improve things, I suspect.

Mr. MILLER. So if we reduce the likelihood of low birth weight babies, we believe we might have some impact on SIDS children, right?

Dr. VALDES-DAPENA. I believe it will.

Mr. MILLER. If we reduce smoking in mothers during pregnancy, we think there might be some—so you're really talking about general health characteristics of the mother during the pregnancy?

Dr. VALDES-DAPENA. Yes, because those are the only factors we know now.

Mr. MILLER. You mentioned that in every nation the victims are the children of those mothers that are most deprived socially and economically. That doesn't mean that all SIDS deaths occur in socially and economically deprived families, but that the greater concentration is there.

Dr. VALDES-DAPENA. As Mrs. Garcia mentioned, this phenomenon happens around the world. In Australia, for example, the group that suffers the most are the Aborigines there.

Mr. MILLER. Is that the greatest predictor then?

Dr. VALDES-DAPENA. It certainly is a risk factor, a big risk factor. But the majority of babies who die like this are big, healthy, term babies who come from average families. It's just that the little tiny baby who is born in the poor family has a much higher risk of being the victim.

Mr. MILLER. OK. I guess I'm missing something here.

Dr. VALDES-DAPENA. The numbers, prematurity is not a factor in the majority of cases of sudden infant death syndrome. But premature babies have a big risk.

Mr. MILLER. That goes back to whether or not, when the Federal Government is making an effort in the general health of pregnant women, we're going to capture the universe of children likely to succumb to SIDS.

Dr. VALDES-DAPENA. We will influence it somewhat on those numbers of babies who have pregnancies that aren't great.

Mr. MILLER. What can you say about the smoking correlation that you brought up in your testimony?

Dr. VALDES-DAPENA. You mean to speculate on what is the association?

Mr. MILLER. Well, have we ruled out smoking? You state that 70 percent of the mothers smoked in one case, and in the control group the figure was 40 percent. What does that tell us, or not tell us?

Dr. Valdes-Dapena. That tells that that, in ways we don't understand, cigarette smoking has an adverse influence on the birth and development of the unborn baby. That's as much as we know. How that works, we're not sure, whether the smoke affects the blood vessels that supply the wall of the uterus and, therefore supplies the baby's oxygen is unknown.

Mr. Miller. Are we doing any additional research there?

Dr. Valdes-Dapena. Not that I'm aware of.

Mr. Miller. We're not doing much research at all on this, are we?

Dr. Valdes-Dapena. Directly on target, only $600,000 was allotted for last year. As I indicated, the one study alone was asking for $300,000. That would have been half of all there was.

Mr. Miller. So that's the total Federal effort for directly related, targeted, SIDS-related research.

Dr. Valdes-Dapena. Right now.

Mr. Miller. And this other "catch all" effort, which I support in terms of trying to improve the general health of pregnant women, may or may not spill over?

Dr. Valdes-Dapena. It probably will have some influence, but it is not directly targeted on the subject.

Mr. Miller. You indicated that if the Federal response was the same to other grant proposals and researchers who are making an effort in this area, as it was in this one case, in looking at the brainstem, you thought that that would discourage good researchers from even making an effort—forget being turned down—but from even making an effort.

What is it we would need to do to encourage those talented people to participate?

Dr. Valdes-Dapena. In 1981, there was $3 million available for directly related research. Researchers need money to conduct these sophisticated studies. They're not going to apply if they know there's not that kind of money around for them to obtain. Because applying is a lot of work. It's a tedious job. It's almost like writing a book.

Mr. Miller. Would the difference between $600,000 this year and $3 million be a significant difference in terms of getting people to apply?

Dr. Valdes-Dapena. Yes.

Mr. Miller. The $3 million, is that a realistic figure in terms of the capabilities of people to conduct this research?

Dr. Valdes-Dapena. Yes.

Mr. Miller. Thank you.

Mr. Garcia. Mr. Coats.

Mr. Coats. Thank you. I would like to follow up on Chairman Miller's questions because I'm really confused about this funding for SIDS.

Dr. Dapena, you seem to indicate here that the only amount of money going directly to SIDS-related research is about $600,000, down from $3.4 million. Yet I have the report from the hearing of the Subcommittee on Appropriations, Labor, Health and Human Services and related agency appropriations for 1986. It categorizes Sudden Infant Death Syndrome obligations for 1985 that go to the NICHD at $19.5 million, with $1.6 million going to the National Institute of Neurological and Communicative Disorders and Stroke—and I appreciate that some of this is not directly related—with another $100,000 going to the National Heart, Lung and Blood Institute.

Some of this money is surely being applied to research that pretty directly—even though it might not be line-itemed as a SIDS function—surely some of this is going to SIDS research. I guess maybe Dr. Cats is the one I should ask on this. Could you clarify that for me?

Dr. CATZ. There is confusion. The definition was given by Congress. Actually what it means is that research coming into the system, that carries in the title SIDS, whatever, or in the aims of SIDS, will be triggered and picked up specifically by the system.

However, there are many others in which the researcher is doing very good work looking at the development of the brainstem, for instance, and he doesn't realise that it might be very well related to SIDS. It is our obligation to look at that and making the bridge between those things. That is why we feel it is a better figure to really consider all of what we learn than just those differences.

Now, the definition of $3 million specific and $600,000 means that the six centers that we have on that huge epidemiological study came to an end or at the peak of their activities and that is the fluctuation that exists in funding. One of the ways of stimulating, we do have a plan. In 1981 we had a 5-year plan in which researchers and other people came in with a plan that we felt would be the appropriate way to address those patients. We will be starting now to do an update, introducing the new research, and making the next goals along the way. So in a way, it's a very active, ongoing process that is continuing.

Mr. COATS. And where do you anticipate that SIDS will fit in that new plan?

Dr. CATZ. Oh, this is a SIDS plan. It's a specific SIDS plan. We have 10 areas that have been identified to the Institute, and SIDS is one specific. Within our branch, Sudden Infant Death Syndrome is one of five top areas that we consider equivalent.

Mr. COATS. I'm wondering if any of the panelists can identify how much private research or university research, medical research is currently being conducted. Does the SIDS Foundation have any figures on how much private research is going on outside Government? We know we have Federal at some level that we're not quite sure we can determine, either related or indirectly related research. We had the question on the State involvement and I should point out that the block grant, I think, Dr. Catz, is increased by $100 million or so in this last fiscal year. Obviously, it's not specifically related again and decisions have to be made as to where those dollars go.

Moving now to private research, can anyone give me some numbers or figures or studies, things that are going on in the private sector?

Dr. VALDES-DAPENA. I know about what the Foundation has done. The National SIDS Foundation last year spent more than $100,000 of its own money on the private support of research. About $90,000 of that went to support the Harvard brainstem study until such time as it could be taken over by NICHD.

Mr. **Coats.** Was the brainstem study specifically SIDS?

Dr. **Valdes-Dapena.** Yes.

Mr. **Coats.** But it wouldn't necessarily be contradictory to the brainstem work that's being done through NICHD, even though that doesn't show up as a specific SIDS line item appropriation.

Dr. **Valdes-Dapena.** Of course, they are now supporting that project at $150,000 a year. That's a big part of their support at the present time of the brainstem research.

In addition——

Mr. **Miller.** Would the gentleman yield for just 1 second for a clarification here?

We have specific brainstem research that's directed at—that's looking for SIDS connections—I'm cumbersome in my words—and we have another brainstem study that may be related to——

Dr. **Catz.** Most likely related, yes.

Mr. **Miller.** Well, that's important.

Dr. **Catz.** Oh, yes; it is. We don't know why those abnormalities are seen by the pathologist. This is an in vivo animal study which might explain some of those things, because obviously this is not a human investigation in which you can put electrodes around the brainstem and measure, you know——

Mr. **Miller.** OK. Let me ask this question of both of you, and I think this will help Congressman Coats and myself.

In a scientific determination, would you make the decision that both of those studies are SIDS-related, one directly and one indirectly? Would you make that decision of scientific determination? I'm concerned here as to whether the research is following the disease in this instance, or whether you're trying to squeeze some research under the letter of the law that says it has to be SIDS-directed or SIDS-related. I was trying to determine whether we're complying with the wording of the law or with appropriate scientific inquiry in developing research here.

Dr. **Valdes-Dapena.** The study being done at Harvard is directly related as being done on the brains of babies who died of SIDS.

Mr. **Miller.** But is it accurate to suggest that this other research is SIDS-related?

Dr. **Valdes-Dapena.** I don't know. Is that Kevin Wynn's project?

Dr. **Catz.** No, it's Dr. Larson.

Dr. **Valdes-Dapena.** It's probably related and will probably shed some light on the subject. But it isn't using the brains of babies who died of SIDS.

Dr. **Catz.** No. It's animal models.

Dr. **Valdes-Dapena.** It's an animal model.

Mr. **Miller.** So there's a little bit more than $600,000.

Dr. **Catz.** Well, if we count the figures for 1985——

Mr. **Miller.** I just wondered—I mean, Congress is great at keeping a double set of books. We take our action when we relate them to 9 or 10 different constituencies and we tell all these people we did things for them. I just wonder what's going on here, whether we're taking credit for other people's work. Some of those people making the scientific inquiry don't see themselves as related to the SIDS question or looking for that connection, whether or not that is as valuable research as that conducted by people who are directly engaged in the SIDS inquiry. I'm taking other people's time here.

Dr. **Valdes-Dapena**. The Harvard project is being supported at the rate of $150,000 per annum. I don't know how much is going to the animal study. But when I used the figure $600,000, that was all NICHD directly related funds available.

And a lot needs to be done with the neurosciences. One has to get into neurohistochemistry, and that's just starting. That takes money.

Mr. **Coats**. Well, it's true, though, that the money appropriated for specifically related SIDS research could result in a breakthrough in some other area and might benefit some other type of disease, so we have cross-purposes here.

That brings me to this question, Dr. Catz. How do you at NIH communicate among your various departments and divisions about your research and how it might impact on other diseases and the treatment of other——

Dr. **Catz**. We do have good communication with other institutes, my colleagues in other institutes, Miss Norris and so on, and with researchers in the field. We try to keep updated. We are really trying to go to professional meetings and trying to stimulate good researchers that are not really thinking SIDS but are thinking, for instance, today neurosciences, to really go to this area which needs so much work. So in a way, you know, we try to keep up on that and we do communicate.

Mr. **Coats**. I know my time is about up. Just to finish up my previous question, you mentioned the one project underway on brainstem research that is partially funded by NICHD. Do we have knowledge of what the total is around the world in terms of private research or foundation research? Is your foundation the only one?

Dr. **Valdes-Dapena**. Our foundation is the only one that is supporting from the private sector to that extent, over $100,000 a year.

Mr. **Coats**. Are other foundations contributing to SIDS research that you're aware of?

Dr. **Valdes-Dapena**. I think there's a little bit of it going on in other places. Like in Great Britain, they're supporting it certainly.

Mr. **Coats**. Are other studies going on, other than the Harvard project?

Dr. **Valdes-Dapena**. With regard to brainstems?

Mr. **Coats**. No, with regard to the whole SIDS problem.

Dr. **Valdes-Dapena**. Oh, yes, other studies are going on around the world. But the amounts of money available are not big at all. There is just not very much anywhere.

Mr. **Coats**. Thank you, Mr. Chairman.

Mr. **Garcia**. Just let me say we're going to take a short recess. Before my colleagues leave may I have your attention. There are about 20 or 30 people still outside this room. The reason why we didn't go into the main hearing room was because the full Post Office and Civil Service Committee was meeting this morning.

What I'm going to ask all of you to do—and I guess we can do that without a problem—is that after this 10-minute recess we will reconvene in room 311, which is just down the hall.

[Whereupon, the hearing was recessed, to reconvene in room 311, Cannon House Office Building.]

Mr. Garcia. What we're going to try to do is finish with this panel within the next 10 minutes. We have two more panels to go. The last panelists are two couples who have lost their children. I really want to get their testimony because I think that's going to be absolutely crucial to the purpose of this hearing.

I would yield to my colleague, Mr. Walgren, if there are any questions he would like to ask, and then to Mr. Wolf.

Mr. Walgren. Thank you, Mr. Chairman. I think I can be very brief.

As I understand it, these services break down into two components: one, counseling and essentially social services, and the other, the medical research on the problem. With respect to whether the effort has increased or decreased, I would like to ask unanimous consent if you might include in the record two pages of the Comptroller General's report on maternal and child health block grants which describe the sudden infant death syndrome services and the program reductions which reflected changing priorities when they were block granted to the States, and that is in that report on pages 49 and 50 and 51.

[The GAO report follows:]

BY THE COMPTROLLER GENERAL

Report To The Congress

OF THE UNITED STATES

Maternal And Child Health Block Grant: Program Changes Emerging Under State Administration

The Omnibus Budget Reconciliation Act of 1981 consolidated eight categorical programs into the maternal and child health services block grant and shifted primary administrative responsibility to states. States continued to support activities similar to those funded under the prior categorical programs although some changes were made to program priorities and services offered. States tended to assign higher priority and make fewer program changes in areas where they had considerable previous involvement.

The availability of prior categorical grant funds in 1982 mitigated the impact of reduced maternal and child health block grant funding and enabled states to reserve block grant funds for the next year. As categorical funds diminished, however, state and other sources of funds began shouldering a greater share of program costs. In 1983 the emergency jobs bill legislation substantially increased the maternal and child health appropriation and should help promote relatively stable funding in 1984.

States' health agencies were carrying out block grant responsibilities and management improvements were reported in some states. Various methods were used to obtain public input, and the involvement of state elected officials and interest groups had increased. Most state officials rated the block grant more flexible and desirable, while about half the interest groups responding preferred the prior categorical approach.

UNITED STATES GENERAL ACCOUNTING OFFICE

GAO/HRD-84-38
MAY 7, 1984

SUDDEN INFANT DEATH SYNDROME SERVICES--PROGRAM REDUCTIONS REFLECT CHANGING PRIORITIES

SIDS, often known as "crib death," is the sudden and unexpected death of an apparently healthy infant. In 1974 the SIDS program was established to provide counseling for families of SIDS victims and public education for health professionals as well as the general public. Other services offered included autopsies, providing monitoring equipment and training, and research projects into the causes of SIDS. Services are provided by a variety of organizations, including state agencies, universities, local health departments, hospitals and clinics, and other nonprofit entities.

The SIDS program area is one of the smallest within the total MCH program, with 1983 expenditures representing about 0.2 percent of total MCH expenditures for the states we reviewed. SIDS services were provided in all 13 states at some time during our review, although expenditures were generally on the decline. As shown in appendix IX, for the 12 states that provided complete expenditure data since adopting the block grant, expenditures decreased in 8 states and increased in 4.

Several states reduced or discontinued expenditures for specific SIDS projects, often citing the need to fund higher priority programs. Additionally, some noted that although expenditures were down, services to SIDS families would still be available through other related programs. Some examples follow.

--Colorado reduced its program expenditures by 35 percent between 1981 and 1983 because officials do not consider SIDS a high priority and are encouraging the service provider to secure alternative funding.

--Florida reported that, due to higher priorities, it has reduced its public education efforts and discontinued counseling services for families of SIDS victims. Counseling, however, will still be available on an as-needed basis through public health nurses.

--California officials said that less emphasis is being placed on SIDS because no reliable method is currently available to screen for or prevent SIDS, counties already have a well-established system for following up and counseling families of SIDS victims, and state MCH staff is available for consultation on an as-needed basis. Therefore, the state opted to discontinue SIDS funding for separate projects and instead merged SIDS activities with its general MCH operations.

--New York eliminated funding for SIDS family counseling and research projects because of higher priorities and because services could be provided as part of its general MCH program.

--Michigan eliminated in-service training for local and community health department staffs and reduced its public information efforts due to a lack of funds.

In four states expenditures for SIDS increased with the largest percent increases in Pennsylvania and Mississippi. For example, Pennsylvania increased expenditures by $102,000, or 86 percent. Mississippi just began its program in 1982, offering family counseling and public education. Iowa also offered a new SIDS service in 1982--training parents how to use equipment to monitor children identified as having potential problems.

We visited service providers in Colorado, Michigan, and Washington. The provider in Michigan is a county health department which offers a wide array of health services, including a public health clinic, a paramedic unit, and Medicaid screening, child nutrition, sickle cell anemia, and SSI services. The health department's 1983 budget was $7 million, of which less than 0.1 percent was for its SIDS program. The county has routinely provided SIDS services for years through its public health nurses who make home visits. The county was aware that funds received from the state contained block grant funds but was not aware how much.

The Washington service provider is a nonprofit orthopedic hospital and medical center for children offering counseling, educational, and SIDS coordination services statewide. The hospital is funded almost totally through private grants and payments with a 1982 budget of almost $48 million, of which hospital officials estimated that 0.3 percent is for the SIDS program. In addition, they reported receiving MCH block grant funds of $17,000 and $60,000 in 1982 and 1983, respectively.

Neither the Michigan nor Washington service providers reported significant changes in clients served, staffing, or service levels in the past 2 years. This may be due in part to the fact that, for these providers, the SIDS program is a small part of a large and multifaceted program.

The Colorado service provider, however, serves as an example of an agency's efforts to maintain its level of services despite declining state support. State officials do not consider the SIDS program to be a high priority. According to the project director, this is because of its low incidence (about 100 cases per year) and difficulty in measuring program impact. In view of declining state support and the state's advice to seek alternative funding, the service provider is looking to become financially independent of federal and state funding.

This nonprofit organization provides information and counseling to families as well as SIDS education for medical professionals and the general public. Although its total funding increased from $57,000 in 1981 to almost $74,000 in 1983, there has been a major shift in its sources of funds. In 1981, a federal categorical grant totally funded the program; but since the grant expired, the state has replaced only $30,000, or 41 percent, of the program's 1983 expenditures with the remaining funding being obtained from private grants and payments. The program experienced an additional financial burden when the local hospital, which operated a similar counseling program, withdrew its support which had included free office space and various medical and administrative services.

The provider's professional staff level has remained essentially constant, while the caseload per staff member has increased; without autopsies that the hospital had conducted for this service provider, many cases are incorrectly classified as SIDS, according to project officials. As a cost-containment measure, the service provider is deemphasizing such indirect services as educational outreach to the community and professional training, while maintaining such direct services as family counseling. More severe effects have been avoided by expanding the use of volunteers to provide counseling services and obtaining additional revenue through private fund-raising activities.

Mr. **Walgren.** In summary, they looked at 12 States, 8 of which showed decreases essentially because when those programs were put in the block grants they were unable to compete in priority with the others. Consequently, there were certainly decreased services available in those States.

The second part of this, whether there is increased or decreased funding for the medical side of the research, I wanted to raise with Dr. Catz—you used a $17 million figure in your presentation which is not in your written testimony. Could you describe where there $17 million comes from that you mentioned verbally?

Dr. **Catz.** Certainly. We do have a sheet, which I thought had been provided—and obviously it has not—which talks about the budget that we had had since 1980 up to today, divided into SIDS specific—we talked SIDS-general and we had explained that. It is the bottom line of total SIDS research which has moved from $16,800,000 in 1980 to the preliminary numbers for 1985 being $17,845,000, with SIDS-specific being above a million dollars in that category.

But what I would like to mention is that to fund research grants we depend on what is submitted. The fluctuation might reflect very well the type of applications that are submitted, and then are reviewed by peers of the applicants.

Mr. **Walgren.** But you're showing a million in 1985—that's not far off the $600,000 figure that was mentioned. But you indicated that you felt that the $600,000 reflected a decline in the research center activity.

Dr. **Catz.** The epidemiological studies and other contracts came to an end and, therefore, the money that was allocated for that which had SIDS-specific within the title, or the aims, decreased the total amount that was available.

Mr. **Walgren.** Now, I would like to then ask, what's the perspective from the research centers view, if anyone is able to give us that? The statement is that the research center component of this effort has declined because certain research was phased out.

Can anybody speak to whether the research centers have been not participating as they had in earlier years?

Dr. **Mandell.** Let me just say from a clinician's point of view that, as a clinician, this is the most frustrating of problems. You know, I guess we have to ask ourselves what are we doing, what are we searching for. We are searching for an answer to the sudden infant death syndrome. It has been extremely elusive.

For us to focus, for example, on just one study here, and expect that brainstem study to find the answer, I don't think is fair. There must be a significant amount of research to find an answer. Researchers must be stimulated. There must be funds to stimulate that research. It is not available. Three million is not even enough if we're talking dollars.

It seems to me that when we're talking about what is direct and what is indirect, we need to ask ourselves a little bit about what that means. It seems so basic, but we don't know why babies die. You know, there are only several ways to die—either your heart stops or you stop breathing or your brain stops functioning. Any kind of research that goes into cardiorespiratory or any brain physiology can say this is related to the sudden infant death syndrome.

Whether it really has the benefit that we want to find the answer to sudden infant death syndrome, we don't know.

When we're talking about direct, SIDS-related research, that's when I think we begin to focus on finding the answer to sudden infant death syndrome. That's what we're talking about today.

Mr. **Walgren**. Thank you.

Mr. **Garcia**. Dr. Rowland.

Dr. **Rowland**. I appreciate your comments very much about not focusing in one area. We thought at one time malaria was caused by bad air. Later on we found out malaria was caused by mosquitoes. So I think it is very important to look at the overall picture and not just focus on one particular area.

I want to change the focus just a little bit, Dr. Mandell, to what you were talking about earlier, about these young parents that have a child that dies with crib death, particularly if it's a first child; then all the guilt and fear that they deal with, the fear of having another child. It's not really unusual, I don't believe, to have two children in one family with crib death. Maybe there is some familial relationship which even more focuses the attention in this area.

Let me ask you about infant monitoring, the monitoring of respiration, cardiac monitoring, how much good you think that does. Can you give any information to us about how monitoring may have helped these couples in dealing with this problem?

Dr. **Mandell**. This is a very difficult clinical problem. The answers are unknown. I know that we happen to be in a situation where many monitors are being used. Whether or not they, in fact, are preventing a significant number of deaths is really unknown. It is something that is plaguing clinicians because we don't know and we're not sure any more exactly who to monitor; we're not sure who is at risk; we're not sure if monitors are, in fact, helping those who are at risk.

We know certainly that they help some children. How many children is an unknown. But because it's unknown, because we're not able to say how many and who is at risk, we tend to monitor more children. So it's a very difficult question. I wish that I had the answer to that question.

Dr. **Rowland**. Do you recommend, if there has been one crib death in the family, that subsequent newborns be monitored?

Dr. **Mandell**. This differs in different parts of the country. What happens in one area is not necessarily what happens in other areas. There is a real difference of opinion as to whether or not these children should be monitored.

Dr. **Rowland**. Mrs. Garcia, what about the situation with your son and daughter-in-law?

Mrs. Jane **Garcia**. We now have a new grandchild and he's 6 months old, thank God. The monitor came home from the hospital with him. My daughter-in-law prepared herself, and my son as well. It is a tremendous emotional trauma to have a life come into this world that is going to be attached to a machine; to be constantly reminded of Alex' death every day with that blue suitcase in the nursery. I really would go to bed at night and worry about the value, the medical value of this cloud hanging over a new life. We were trying so much to separate our past experience and psyching ourselves up to prepare ourselves for the death of another child.

The doctors felt that after the first months it was no longer really necessary to keep him attached to a monitor. He is not being used as a subject for research, not because we have any objection to it but because there really are no facilities. There is no money and there is no program in the area of Albany, NY, or any medical school working on this. So there is no way we can use our case, other than what we're doing here today, to help in a more active way through research.

I would like to make an additional comment. Years ago sufferers of Alzheimer's disease thought that this was just a normal aging process. I think today that because SIDS has been around since biblical times, since the beginning of man that it may be perceived as a major health issue. It's not a recent invention and it wasn't invented by the National SIDS Foundation. But what is different now in this century, in the last 23 years that the Foundation has existed, is that for the first time there's a separation between childhood diseases as medical conquests have occurred; we have been able to eliminate measles as a scourge, small pox, tuberculosis, whooping cough and any one of the other childhood—all of these things we have vaccines for. So now we've been able to isolate this other cause of death and it doesn't seem to be related to any of these other childhood diseases. Why should we not provide the necessary funds to study and examine the causes therein. That's what it's all about and what we're really concerned about. The need is increasing, however, the funds are decreasing to specifically study this. That, I think, is the crucial issue here before us.

Dr. **Rowland**. Mr. Chairman, I think there is, even though it's grossly inadequate, some research going on into the etiology. But I'm really concerned about those couples who have had a child like this. There doesn't seem to be any general agreement about what needs to be done in counseling these parents on what to do from the standpoint of protecting a second child they may have. I would like to see more attention focused in this area also.

Thank you very much.

Mr. **Garcia**. Mr. Wolf.

Mr. **Wolf**. Thank you, Mr. Chairman. I'll be very brief because I know your time is short. However, I want to ask the question about warning and monitoring.

I want to thank you and thank the panel. It has been one of the better hearings I have attended. When my dad was in World War II, I lived with my aunt. One day my cousin died in the crib. I was just a little boy, but I remember my uncle rushing him to Bryn Mawr Hospital. It was a very difficult time. I was small and don't really recall a lot of the facts, but I know that we never knew the reason why. Obviously, this SIDS was the case.

I have two questions? One, I understand there were 7,000 SIDS cases in the United States, last year. Is that figure increasing or decreasing?

Dr. **Valdes-Dapena**. As far as we know, in the last 10 years that number has neither increased nor decreased.

Mr. **Wolf**. So all the efforts to date really haven't made that much of a difference?

Dr. VALDES-DAPENA. As far as we can tell, the number has not changed substantially.

Mr. WOLF. Do you know what that number would be worldwide?

Dr. VALDES-DAPENA. I don't.

Mr. WOLF. Does anybody know?

Dr. CATZ. No. Unless people do keep statistics in other places, it would be very hard to come by because you depend on the diagnosis as well.

Mr. WOLF. It would be well over 100,000, I would think.

Dr. VALDES-DAPENA. In European countries we are aware of the fact that it is pretty much the same as it is here—2 per 1,000 babies born alive. But you can't get any figures from Third World countries because they don't have the mechanism set up to count and to do the adequate autopsies.

Mr. WOLF. But based on the testimony of Dr. Catz, it hits everyone equally. You could almost extrapolate, couldn't you, and figure what the worldwide number is?

Dr. VALDES-DAPENA. I don't know that any figures exist.

Mr. WOLF. Well, could you do that, just for the committee to have that on the record?

Dr. CATZ. We could try, but it wouldn't be—I don't know that it would be representative.

[The information follows:]

WORLDWIDE INCIDENCE OF SIDS

As previously stated, it is not possible to provide an accurate figure for the total number of SIDS deaths worldwide. Reliable SIDS incidence data are not available from most of the countries of the world. The lack of data is not limited to just the "so-called" developing nations.

To comply with the request for a figure of the worldwide incidence of SIDS we studied the available data and developed estimated incidence rates ranging from 1.5 to 2.5 per 1,000 live births. The current estimate of the U.S. incidence rate is between 1.5 and 2.0. Using the United Nations estimate of 128.5 million worldwide births in 1985, and our incidence rate range of 1.5 to 2.5, we derive an estimate of between 193,000 and 321,000 worldwide SIDS deaths in 1985. We would suggest that the average of these estimates—257,000—is a reasonable, probably conservative, estimate of the number of worldwide SIDS cases in 1985.

Mr. WOLF. You would have to footnote it and explain that this was extrapolated, but if you could do that, I think that would be an interesting figure. I think maybe that would be one way to generate a lot more support.

The last question is so general that maybe you want to just answer for the record. Is there anything that we can do with regard to an educational process to make people more aware of SIDS? I think Alzheimer's disease is a very good example of the effort I am thinking of. Two years ago I didn't even know anything about Alzheimer's disease. Now I'm working on an Alzheimer's respite center in my district. I have met people who have Alzheimer's patients in their family. All of a sudden it's a very important issue. Partly because there was a movie on television about it with Joanne Woodward.

Is there anything we can do from an educational point—this hearing is a good beginning—to get people interested in it?

Mrs. JANE GARCIA. I think there are a number of things we can do. I think education is the prime objective. I think making people aware of the fact that this can happen to them and if it does happen to them they're not alone.

The National SIDS Foundation is beginning a TV campaign in English and in Spanish, to educate the public on SIDS. The foundation has limited funds. And we will be doing other things along those lines. But I think as far as legislation is concerned, I believe a commitment to provide more funds is necessary.

The National SIDS Foundation is committed to fundraising measures in the future because we see the need for doing it ourselves. But we need to have partnership with the Government and with the private sector as well.

Dr. VALDES-DAPENA. I should like to make this one entry before leaving the microphone. We aren't going to solve the problem of crib death until we know why and how it occurs. Indirect research projects are indirect and they're not going to get at that critical core, whereas directly related research—and we need more of it—can approach the critical question.

Dr. CATZ. If I may add something to that, the fact that the Institute is very aware of that and provides within what we receive the maximum attention to the SIDS project. As a matter of fact, of all approved grants that come to the National Institute of Child Health and Human Development, 28 percent during the last year have been funded. For specific SIDS research it was 60 percent, and actually we raised to pay—because it wasn't within the funding range—the research project that Dr. Dapena mentioned, because we realized the importance of it.

On the other aspects of the high risk, the generally related, we are funding at the level of 47 to 56 percent of the approved grants. So the Institute is very aware and wants to put emphasis and is putting emphasis in that particular area.

Mr. WOLF. Thank you.

Thank you, Mr. Chairman.

Mr. GARCIA. Thank you.

I would like to thank the panel.

For the next panel we have Ms. Carrie Sheehan from Seattle, WA, who is the western regional director of the National SIDS Foundation, and Miss Gayla Reiter from Pacifica, CA, who is the legislative coordinator for the northern California chapter of the National SIDS Foundation, and Mr. Parker H. Petit, who is the founder and chairman of the board of Healthdyne, Inc., and the chairman of the board of the American Sudden Infant Death Syndrome Institute. The regional representatives of the National SIDS Foundation will focus on block grants and SIDS-related counseling services, and Mr. Petit will speak to us about the use of home infant health monitoring devices.

I would like to thank all of you for coming today. Your statements will all be entered into the record in their entirety. I would ask you to summarize. There is another panel after this and I appreciate very much your coming here today from as far away as you have.

Dr. ROWLAND. Mr. Chairman, while we are waiting, may I make a comment?

Mr. GARCIA. Certainly.

Dr. ROWLAND. I want to welcome Pete Petit, who I have known for a long time, to this hearing. He also had a tragic experience, as he will relate to you, I am sure, regarding crib death. I have known that he has been involved in infant monitoring for a long time and entered into this area because of the tragedy that he experienced in his family.

I'm going to have to leave because I have a 12 o'clock appointment elsewhere, but I just wanted to thank him, as well as the other members, for being here.

Mr. GARCIA. I thank you for being here, and I know some of the other members will be joining us after this vote is completed. The vote is completed but there was some business on the floor that's still going on.

However you may proceed.

STATEMENT OF GAYLA REITER, SIDS PARENT, AND LEGISLATIVE COORDINATOR FOR THE NORTHERN CALIFORNIA CHAPTER, NATIONAL SIDS FOUNDATION

Ms. REITER. My name is Gayla Reiter and I have submitted a written statement. I am going to just summarize some of my remarks and try to direct them to some of the points that have already been discussed.

This is my husband, Wilfred Scott. We are both very active in our union and have become active in the Northern California Sudden Infant Death Syndrome Foundation chapter since the death of our baby about a year ago. Our baby girl, Layta, died the day after Thanksgiving—November 26, 1984—of sudden infant death sydrome.

We can tell you from personal experience that we've never had a more devastating event in our lives, but perhaps even more shocking was what we found when we began to look into what was being done to find the causes and prevent this tragedy from touching other people. We found that the Federal committment to fund research and support to families mandated by the 1974 SIDS Act, had been abandoned.

I am very concerned both with what has happened in funding for SIDS research and also with what has happened since the block grant program went into effect, because both efforts have suffered tremendous adverse setbacks. Funding for SIDS programs has been disproportionately lowered in both areas. When all of the facts are on the record, each person here will realize that even though SIDS receives less than two-tenths of 1 percent of total funding from the Department of Maternal and Child Health, the SIDS programs have been slashed in a much greater proportion than other MCH programs.

You have all heard the statistics which have so eloquently been quoted. SIDS kills more babies in the first year of life than all other causes combined. And yet we devote so little money to finding its causes and so little support and attention to helping the families deal with this tragedy.

I recently read the Senate hearings that Senator Cranston conducted in 1978, also the hearings in 1973 before passage of the SIDS Act. At that time there were significant problems in the

States. Many parents were still being arrested for suspected child abuse when their babies die of SIDS. It was due to a clamoring and an outcall that the hearings were held and the 1974 SIDS Act was passed.

Now, what happened in those hearings was that Congress pointed to the fact that the year prior, which would have been 1973, only $603,000 had been spent for SIDS primary research. They termed that outrageous. I think it is indeed ironic that we look at today's funding levels and see that we're about at that same level. Ten years after passage of the 1974 act, we have regressed to the point that we were originally when we felt the need was so great; the Federal effort of disastrously inadequate.

When we talk about SIDS primary research we're talking about a very wide subject. It is not narrow in scope because SIDS primary research as defined by NIH covers the investigation of low birthweight babies, pregnancy, fetal development, prematurity, neonatal adaption, indices of risk for SIDS, studies of grief, family support—it's a fairly broad area. And yet, only $657,000 was devoted to it last year, less than $600,000 is budgeted this year. How can we reconcile that grossly inadequate amount of support?

I question the priorities of how the meager amount was allocated. I also question the manner in which NIH is distributing the money. After several months of trying to obtain a breakdown from NIH (without success) of how the funds were allocated, what research projects were being funded, I finally asked Congressman Miller to obtain that information. He got it within a week, whereas I had not been able to obtain it in months. They furnished him a statistical breakdown and it showed, for instance, in SIDS primary research, that Biodyne, Inc. had received a grant of $497,000 for last year to develop a motion sensitive monitor.

That constituted well over 50 percent of the total amount funded for primary research for the entire year. I think we have to question where the priorities are. This is a highly controversial area. I am not going to address whether or not monitors are a worthwhile subject of funding, but certain questions arise about why such a large percentage of the funds are devoted to one project when so many others have gone unfunded. We need congressional oversight of this area.

In addition to the problems regarding research, there is the very severe adverse impact of the block grant concept on SIDS support services in the various States. Senator Cranston, in 1981, when he was asking for an extension of the SIDS Act stated in the Congressional Record that the primary progress we had made in SIDS research had come through the information-gathering systems that had been created through passage of the 1974 SIDS Act. Unfortunately, most of that progress has been halted because of the fact that many States have either substantially reduced or cut out their programs altogether.

The May 1984 GAO report highlights some of those problems. I understand the Congressman is having that portion of the GAO report entered into the record.

I can tell you about California and what has happened in California directly. Under block grant decisionmaking, California decided that SIDS was not a high priority, so they completely slashed all funding to the SIDS, project which had previously been catergoically funded by the Federal Government. Previously there had been a SIDS project that was very professional. They funded writing and publishing of pamphlets in several languages; they held seminars; they taught classes for professionals such as firemen, ambulance, and hospital personnel. They produced movies and they distributed these. Their services were extremely useful—and yet their entire staff was dismantled. They were also responsible for gathering information and statistics on SIDS cases throughout the State. They no longer have any staff to perform any of these functions. The SIDS project had had five full-time professionals, three clericals, and student aides who directed statewide SIDS support services. All of that is gone now.

If you look at State after State after State, this story is repeated in numerous instances. New York halted funding for counseling and research projects because they felt other problems had higher priority. Michigan eliminated all inservice training, as well as public information efforts. They didn't have enough money. Florida discontinued services for families because they felt they had higher priorities and there weren't sufficient funds to stretch for their meager budget. Colorado reduced their expenditures over 35 percent in 1 year because they had other priorities.

In Utah, they eliminated funding for social workers and nurses in the SIDS project, leaving only one person part time to cover the entire State. They also drastically reduced money for travel, publications, seminars, and counseling. The story is similar in State after State. The needs are great, but little is being done to meet these needs.

The heartrendering impact of SIDS is not being addressed in an organized or effective manner. We need congressional oversight on how the moneys that are being spent on research are being spent. We need oversight in how NIH is setting their research priorities. We need a concerted congressional investigation of the impact of the block grant program on information and counseling and educational efforts in the State.

I wish to thank all of the Congressmen for taking an interest in this very important subject. I especially want to thank George Miller for sponsoring House Joint Resolution 322 and for Congressmen Garcia, Miller, and Waxman for holding these hearings.

[The statement of Gayla Reiter follows:]

TESTIMONY FOR HEARING
ON H. J. RESOLUTION 322

Subcommittee on Census and Population
Select Committee on Children, Youth and Families
Subcommittee on Health and the Environment

Thursday, November 14, 1985

Gayla Reiter
SIDS Parent, and Legislative Coordinator for the
Northern California Chapter, National SIDS Foundation

My name is Gayla Reiter. I am a SIDS parent and am currently the Legislative Coordinator for the Northern California SIDS Foundation. My husband, Wilfred Scott, and I lost our baby to SIDS nearly a year ago on 11/26/84. The loss of our baby to SIDS was the most devastating event in our lives --- having a far greater impact than the death of both of my parents, tragic deaths of close friends, serious personal injuries, health problems, etc. I was determined, however that Layla's death would not be in vain, ... making a commitment to do anything I could to prevent other parents from experiencing a similar tragedy.

When I began to investigate SIDS and what was being done to discover its causes as well as the programs that existed to collect information, provide education, etc., I became quite concerned. It soon became clear that budget cuts had adversely impacted on research as well as educational support and information gathering mandates of the 1974 SIDS Act.

As you know, federal efforts in the area of SIDS began with the 1974 SIDS Act, Public Law 93-270. This act established 3 basic programs related to SIDS. The first was a program of research (with annual reporting to Congress) specifically related to SIDS through the National Institute of Child Health and Human Development (N.I.C.H.D.) The second involved developing a program to educate the public and supply materials related to SIDS to health care professionals, law enforcement personnel, and the general public. The third was authorization for the government to make grants and enter into contracts for the collection of data and information related to the causes of SIDS as well as providing for counseling/information services to families of SIDS victims. In passing this legislation, Congress went on record as deploring the lack of information, research or services devoted to SIDS.

SIDS kills between 6,500 and 10,000 babies each year (roughly 30 babies die each day with more babies dying annually from SIDS than from birth defects, cerebral palsy, cancer, heart disease -- virtually all other causes combined). Despite these alarming statistics, we are spending less on primary research for SIDS than at any time since passage of the 1974 SIDS Act. One of the facts that was pointed to in dismay during hearings on the original SIDS Act was "minimal federal involvement in research." Several Congressmen decried the fact that the government had only spent $603,575.00 on SIDS primary research the prior year (i.e. 1973 - the year prior to passage of the act). It is indeed ironic that last year's funding for SIDS primary research was only $657.000.00.

SIDS primary research encompasses a wide range of topics including research in low birth weight babies, indices of risk for SIDS, pregnancy, fetal development, prematurity, neonatal adaptation as well as studies to help families deal with SIDS.

Senator Alan Cranston, when introducing Senate Bill 560 to extend the authorization for SIDS in February 1981, noted that we had made progress since 1974, but indicated that the $5,380,000.00 budgeted for primary research that year was clearly inadequate. He would undoubtedly be alarmed at current funding levels -- amounts budgeted have plummeted. For example funding for SIDS primary research was $2,763,000.00 in 1982, $1,780,000.00 in 1983 and a mere $657,000.00 in 1984. When one analyzes the data furnished by N.I.H. of its SIDS related grants, it appears the majority of all monies expended for SIDS specific research went to Biodyne Inc. for development of a motion sensitive apnea monitor. The issue of monitors is a highly controversial area and without addressing those issues, it would appear questionable to expend such a large portion of the total budget on a single research project. Certainly, it appears there is strong need for Congressional oversight both on the total amounts expended for research as well as the manner of disbursements and criteria used by N.I.H. We need planning and coordination of research projects to gain the maximum from monies expended.

In addition to cuts in funding for research, there have been serious declines in allocations for counseling, education, collection of data, autopsies, funding of SIDS Projects, etc. Senator Cranston indicated in the 2/24/81 Congressional Record: "much of the progress made in SIDS research in recent years has resulted from the increased SIDS death information and data arising from the information and counseling programs." Yet, once categorical funding for SIDS stopped and the block grant concept was substituted, much of the collection of data, educational and other locally based programs were either significantly cut back or terminated. Several counties (including the one we are in right now) felt monies previously spent on SIDS could be better spent elsewhere -- they eliminated their SIDS program. Though federal monies were given, albeit in diminished amounts, to each state which had a SIDS project as of 1981, no monies were allocated nor provisions made to expand SIDS programs in areas which had none operational by 1981. At least 14 states had no SIDS projects in 1981.

At a recent conference in Albuquerque, Gerry Norris (Director of SIDS Program for the Department of Maternal and Child Health) described the frustration in her office's inability to track what had happened with SIDS programs in each state since block grants were effectuated. Many area suffer generalized shortage of staff in their health programs. Hence positions formerly devoted to SIDS projects full time have often been eliminated with SIDS responsibilities being added to the already extensive duties of the remaining staff. The overall impact is frequently little or no time or planning devoted to SIDS issues.

Most of the information which documents the adverse impact of the block grants is anecdotal, but it appears to constitute a distinct pattern of declining service throughout the United States. For example, Carol Farina, the recently retired Director of the SIDS project in California, described how her program had been devastated by the switch to the block grant concept. Prior to block grants, her staff consisted of 5 full time professionals, one to two full time clericals plus several student aides. They had done a quarterly newsletter, wrote, published and distributed pamphlets in several languages, conducted numerous seminars as well as collected data on SIDS deaths. All of these services have been halted due to their staffing cuts. Once federal reporting requirements tied to maintenance of categorical funding cease, there is no guarantee that states will continue any of their former SIDS related services. In fact many states pass responsibilities for making the cuts onto counties, hence there is frequently not even statewide coordination of data/services.

Money for the various ancillary services has also been sharply curtailed. A SIDS parent on our Board who works for Alameda County reported that a mere $13.00 is allocated in his county per SIDS death. With this the county is to perform autopsies, provide counseling to SIDS parents, furnish pamphlets and collect information (like completing questionnaires concerning the child's health, the mother's pregnancy, etc.) Obviously it is an impossible task given the funds allocated.

Several of the participants in the Albuquerque conference described similar problems in their own states. Frances Frost, the Director of the SIDS program in Utah described how block grant funding had forced the removal of the social workers and nurse from their SIDS project leaving only 1 professional to administer the program. But staffing cuts were only the tip of the iceberg: travel money was drastically cut as were funds for counseling and educational services such as pamphlets, training, seminars, etc. Their small budget was further diminished by the requirement that they transfer to the Medical Department, $125.00 per SIDS death whenever a coroner performs an autopsy. Regional Directors for the SIDS Foundation from the Eastern and Central United States described similar scenarios in their states. Staffs and monies to administer SIDS programs have universally been cutback, or in several instances, eliminated altogether.

Specific authorization for SIDS funding ended in 1984 -- the Senate has retained report language which says the SIDS Clearinghouse is useful, but its future rests with the whim of a large bureaucracy. The heart rending problems associated with a SIDS death are not being addressed in an organized nor effective manner. We desperately need renewed Congressional intervention and action -- I urge you to consider holding additional hearings to take a hard look at the amount of funding for SIDS research as well as the type of research being funded. Additionally, I ask that you review and closely study the state of SIDS programs in each state -- how has the block grant concept impacted upon service delivery? What needs exist in information gathering, educational outreach, parent support and counseling, training, establishment of and/or use of uniform autopsy protocols, writing, publishing of and distribution of SIDS materials, data collection, etc.?

I thank each of you for the time and concern you have demonstrated for this very important issue. I would especially like to thank Congressman Miller for the considerable energy he and his staff expended in sponsoring and getting passed House Joint Resolution 322.

Mr. GARCIA. Ms. Sheehan.

STATEMENT OF CARRIE SHEEHAN, WESTERN REGIONAL DIRECTOR, NATIONAL SIDS FOUNDATION

Ms. SHEEHAN. Mr. Chairman, my name is Carrie Sheehan and I am the regional director of Western States for the National SIDS Foundation. I manage the activities of 25 chapters, some of them "kitchen table" operations, and others, sophisticated computerized models. Services range from parent support to community education, research and fundraising, to Government relations. I am happy to have this opportunity to express from my perspective some of the concerns regarding the impact of the public sector on our program.

It was parental concern that initiated the SIDS movement for research and support of victims, and these activities by parents and families does continue.

As Dr. Catz stated, the direct grants to States and programs under the SIDS Act ended in fiscal year 1982. The legislation that followed included but did not mandate State MCH block grant funding of SIDS projects or activities. Given that freedom to alter their investments among MCH programs under the block grant, many States did not make substantial changes in their budgets and priorities.

This past summer I had the privilege of working with Geraldine Norris, the Director of the Federal SIDS Program, and others, to produce a new Federal SIDS publication. It also focused on the tragic theme of SIDS impact on the entire community. It points out the toll of blame and guilt and the complexity of responses of the various groups which it affects. It is these very same groups which now are beginning to feel the shockwaves of cutbacks.

Many public health services are being eroded, weakened, or denied. Let me give you a laundry list of some of them.

For example, Hawaii. Initially, $50,000 was budgeted for the five islands, more recently $20,000. This past September the State listed SIDS as "low priority" and all funding was dropped. Unfortunately, at this time the Hawaii National SIDS Foundation chapter is not a strong one. Paradoxically, Hawaii's Division of Maternal and Child Health named the extension of mental health support as a top priority for this year.

MONTANA

The State receives no funding from MCH sources, has no State SIDS program, and only a chapter in Billings to serve the entire State. The State has no allowance for autopsies, which as you know is the only way to identify a SIDS case accurately, and as recently as October a couple whose child died of SIDS was initially charged with murder and exonerated only after a full investigation.

In my own State of Washington, a catch 22 exists, where Childrens Orthopedic Hospital, the site of the project, is the block grant recipient. Hospital personnel needs supercede the project needs, causing a continual reorganization because of lack of continuity. In 1984 there were 181 SIDS deaths in this State. In another western State without a chapter, the Division of Maternal and Child Health has denied a minimal $2,000 each to the seven health districts, with the statement that "the districts will be doing it anyway." There is no legislation in Idaho for SIDS autopsies.

In your State of New York, the SIDS program, with three centers in the State, operated a cost-effective program with an inadequate $218,275 block grant that needed to be supplemented by a State Health Department fund of $120,000. Because that State money had been awarded them, their block grant for fiscal year 1986 has been cut by $10,000. This means they will probably lose the service of one part-time nurse who provides the ongoing education of EMT's, funeral directors, and clergy.

In Texas, the State, with community projects only in the urban centers of Houston and Dallas, receives $20,000 and $50,000 respectively, $70,000 for the whole State. While there is State money for autopsies, a justice of the peace may request an autopsy but is under no obligation to do so. The health department provides information to the public and professionals as requested. According to department statistics, in 1984 only 78 percent of reported SIDS deaths were autopsied. Based on the 2.0 SIDS per thousand live births, Texas would have an extimated 598 SIDS, but only 351 were reported. In a recent court case, the pathologist for the State stated that 95 percent of SIDS are really child abuse.

Finally, if the restoration of categorical funding is not possible, at least I would hope for a federally mandated MCH block grant funding of State SIDS programs. Because of the confidentiality legislation in these States, doors remain closed to programs in the voluntary sector. And if there is no State program, families are oftentimes left without any adequate assistance. Furthermore, without a comprehensive Federal program, there can be no uniform reporting of statistics.

At the turn of the century in America it was not uncommon in many families to experience infant death. In spite of what we have heard today about SIDS, we really do not expect it. And yet, in our country in 1985, the sudden death of an infant becomes a fact, a reality for a family, once every hour.

The poet Robert Frost, who suffered the death of his infant, wrote in the poem "Home Burial: 'The nearest friends can go with anyone to death comes so far short, they might as well not try at all.'" That was true for me 30 years ago when my daughter Molly died. Such reality need not be quite as true today when those victims of SIDS are given scientific facts, compassionate support of other parents, and hope derived from current research. With countless others, we will block the road for any who might return to the past.

[The statement of Carrie Sheehan follows; also included is a letter in response to subcommittee questions:]

TESTIMONY FOR HEARING
ON H.J. RESOLUTION 322

Subcommittee on Census and Population
Select Committee on Children, Youth and Families
Subcommittee on Health and the Environment

Thursday, November 14, 1985

Carrie Sheehan
Western Regional Director, National SIDS Foundation

My name is Carrie Sheehan and I am the Regional Director of the nineteen western states for the National Sudden Infant Death Syndrome Foundation. I manage the activities of twenty five chapters, some of them 'kitchen table' operations and others, sophisticated computerized models. Services range from parent support to community education, research and fundraising to government relations. I am happy to have this opportunity to express, from my perspective, some of the needs and concerns regarding the impact of the public sector on our programs.

It was parental concern that initiated the SIDS movement for research and support of victims, and these activities by parents and families continues. However, recently at the National Conference on Volunteerism in Seattle, the keynote speaker said that despite the impressive increase in volunteerism there is no way volunteers alone can make up for the sharp reduction in government programs in the past few years.

Prior to 1975, the Government's involvement in SIDS was limited primarily to research. However, the SIDS Act of 1974, required the United States Department of Health and Human Services to develop public information and professional educational materials relating to SIDS and to disseminate them to persons providing health care, public safety officials and the general public. These direct grants to states and programs under the SIDS Act ended in FY 1982. The legislation that followed included but did not mandate state MCH Block Grant funding of SIDS projects or activities. Given that freedom to alter their investments among MCH programs under the Block Grant, many states did not make substantial changes in their budgets and priorities.

Regretfully these cuts came the year after the National Institute of Child Health and Human Development report declared, "No systematic studies have yet been undertaken concerning the impact of social, cultural, and sexual factors on the grieving process or on coping with the loss of a family member who dies suddenly and unexpectedly from no apparent cause. Cross-cultural studies might suggest ways of making SIDS a less lonely and traumatic experience through more supportive community attitudes and interventions."

This past summer I had the privilege of working with Geraldine Norris, the Director of the Federal SIDS Program and others to produce a new federal SIDS publication. It also is focused on the tragic theme of SIDS impact on the entire community. It points out the toll of blame and guilt and the complexity of responses of the various groups which it affects. It is these very same groups which now are beginning to feel the shock waves of cutbacks. Many public health services are being eroded, weakened or denied. For example: Hawaii--- Initially $50,000 was budgeted for the five islands, more recently, $20,000. This past September 30th, the state listed SIDS as "low priority" and all funding was dropped. Unfortunately, at this time, the Hawaii National SIDS Foundation Chapter is not a strong one. Paradoxically, Hawaii's Division of Maternal and Child Health named the extension of mental health support as a top priority for this year.

Montana--- The state receives no funding from MCH sources, has no state SIDS Program and only a chapter in Billings to serve the entire state. The state has no allowance for autopsies (the only way to identify a SIDS case accurately) and as recently as October, a couple whose child died of SIDS, was initially charged with murder and exonerated only after a full investigation.

Washington State--- A catch 22 exists where Childrens Orthopedic Hospital, the site of the Project, is the Block Grant recipient and hospital personnel needs supercede the Project needs, causing a continual reorganization because of lack of continuity. Yet in 1984, there were 181 SIDS deaths in this state. In another western state without a chapter, the Division of

Maternal and Child Health has denied a minimal $2,000 each to the seven health districts with the statement that "the districts will be doing it anyway." There is no legislation in this state for SIDS autopsies.

New York--- The SIDS Program with three centers in the state operated a cost effective program with an inadequate $218,275 Block Grant supplemented by State Health Department funds of $120,000. Because that state money had been awarded then their Block Grant for FY 1986 has been cut by $10,000. They will probably lose the services of one part time nurse who provides the ongoing re-education of EMTs, funeral directors and clergy. SIDS claimed the lives of 324 infants in New York State in 1984.

Texas--- The state, with community projects only in Houston and Dallas, receives only $20,000 and $50,000 respectively. While there is state money for autopsies, a Justice of the Peace may request an autopsy but is under no obligation to do so. The Health Department provides information to the public and professionals "as requested". According to Department statistics in 1984 only 78% of reported SIDS deaths were autopsied. Based on the 2.0 SIDS per 1,000 live births, Texas would have an estimated 598 SIDS but only 351 were reported. In a recent court case, the pathologist for the state, stated that 95% of SIDS are child abuse.

Finally, if the restoration of categorical funding is not possible, at least, I would hope for federally mandated MCH Block Grant funding of state SIDS programs. Because of confidentiality legislation in many states, doors do remain closed to programs in the voluntary sector and if there is no state program, families are oftentimes left without any adequate assistance. Furthermore, without a federal program there can be no uniform reporting of statistics.

At the turn of the century in America it was not uncommon in many families to experience infant death. Today, we do not expect it. And yet in our country in 1985, the sudden death of an infant becomes a fact — a reality for a family, once every hour.

The poet Robert Frost, who suffered the death of his infant wrote in the poem, Home Burial

"The nearest friends can go
With anyone to death, comes so far short
They might as well not try at all."

Such is not true now for those victims of SIDS who have been given scientific facts, compassionate support of other parents and hope derived from current research. We have come a long way since my daughter, Molly, died 30 years ago. With countless others we will block the road for any who might wish to return to the past.

CARRIE SHEEHAN
WESTERN REGIONAL DIRECTOR
NATIONAL SIDS FOUNDATION
915 16TH EAST, SEATTLE, WA 98112
(206) 325-7922

December 9. 1985

The Honorable Robert Garcia
U.S. House of Representatives
Room 219 Cannon House Office Bldg.
Washington, D.C. 20515

Mr. Chairman:

The following remarks are in response to the Committee questioning me regarding Education about SIDS as it exists in various states.

Without a State Program large geographical states with sparse populations such as those of Montana, Wyoming and Idaho, literally have no education for public health departments. This year Idaho did hold a teleconference for several hours regarding an update about SIDS research. Because no State monies were available for my participation, the Foundation assumed the expense.

In a recent conversation with the Coordinator of the State Program in Oklahoma, he cited especially the inadequacy of the program in its ability to deal with marital counseling. Education and marital counseling in the private sector costs $50 an hour so is unavailable to many for whom the Project would recommend it.

The New Mexico Project was just notified that their budget would be trimmed by $10,000 dollars reducing it to $53,000 which includes education travel throughout the whole state. The SIDS telephone line avialable formerly, for all in the state is to be discontinued.

The State of Washington also, cut back its 24hour phone service to SIDS families, during 1985, in an effort to 'live' with their budget cuts.

The last major education effort for the widespread health districts in Alaska regarding SIDS information was a 1980 teleconference.

From the instructor of nursing education in San Antonio comes the information that the State Health Department"only pays lip service" to educating parents that autopsies are important and monies are available. The population of the city's metropolitan health district has little formal SIDS management service. The unwritten belief is that "SIDS parents are parents who don't know how to take care of infants."

The Florida Project, once an outstandingone, now only has resources to gather statistics. This coming week the Coordinator of the Louisiana Project will meet with me and the Washington State Chapter to learn of their educational program as the Project located in New Orleans is so minimal it is only a "central register" for SIDS deths in the state.

In conclusion, I would point out that my earlier testimony indicated the probable loss of the service of a part-time nurse to educate the EMTs, funeral directors, and clergy of New York State, the total lack of any educational program in Montana and the termination of the Hawaii Program with the consequent loss of any educational outreach.

While I realize thisinformation is anecdotal and subjective, it is the lack of a comprhensive Federal Program which prevents the gathering of any statistics.

For myself and those families which I represent, you have my deep appreciation of your concern about the issues which affect SIDS management and ultimately those victims of the tragedy.

Carrie Sheehan

Carrie Sheehan
12/9/85

Mr. GARCIA. Mr. Petit.

STATEMENT OF PARKER H. PETIT, CHAIRMAN OF THE BOARD, CHIEF EXECUTIVE OFFICER, AND FOUNDER OF HEALTHDYNE, INC.

Mr. PETIT. Thank you. I am Pete Petit and I have been directly involved with sudden infant death syndrome since 1970 when I lost my second son from a crib death. As a result, I founded Healthdyne to develop equipment that physicians felt would be beneficial in preventing crib death. More recently I have become chairman of the American Sudden Infant Death Syndrome Institute, a nonprofit national organization committed to increasing our understanding of SIDS and finding a means for its prevention. I believe that because of my long-term involvement with this tragic problem, I have gained a broad perspective on SIDS and the support systems used for the management of an at-risk infant.

During the 1960's it was commonly held that the infant that died of SIDS was perfectly normal. However, since 1972, because of increased research funding through NICHD, and the support of the scientific community, we now know that SIDS infants have a chronic abnormality with subtle manifestations that are detectable within the first few days of life. It is also now beginning to appear that this abnormality probably has its onset during pregnancy.

As a direct consequence of improved understanding of SIDS and technological advances, there has been a rapid growth of clinical efforts aimed at preventing SIDS and decreasing morbidity. A very critical element in providing this base has been the development of home monitoring programs. It has been estimated that there is at least $150 million being spent annually, which includes diagnostic studies, physicians' fees, hospital reimbursement, as well as the services and equipment that are related to the home monitoring programs.

As I stated, home monitoring programs have become a critical component in the clinical efforts directed at preventing SIDS. Therefore, it is extremely important to examine the effectiveness of these home monitoring programs.

Within the last month, an international conference was held, and it was attended by key clinicians from around the world. The conference was organized by the American SIDS Institute, Dr. Alfred Steinschneider, and Dr. Andre Kahn from Belgium. The purpose of the meeting was to examine all available data as they relate to the clinical issues of SIDS.

In general, there was full agreement that there are groups of infants who are truly at higher risk to die of SIDS. Furthermore, data was presented from Australia, France, and the United States which indicate that sophisticated home monitoring programs, when employed with selected high risk infants, are associated with a decrease in the incidence of SIDS. However, this conclusion was tempered by the full recognition that these data were obtained employing far from idea research methodology.

It also became clear at this meeting that infants were dying while being provided home health care. However, it appeared that most of these deaths were associated with a lack of utilization of the home monitoring device, even when the device was available in the home. Because of the weaknesses of some of the available data, this clinical group also felt the need for more scientific evaluation of home monitoring programs, the need for assessing means for improving home monitoring programs, and for research to improve the clinical techniques for identifying infants at risk for SIDS. In other words, more applied or clinical research is definitely needed.

Today the needs associated with reducing SIDS and managing at-risk infants are numerous. However, there are two needs that I feel are paramount. First, while the Government was generous during the late 1970's with research dollars for this problem, I feel that the funding was curtailed somewhat early and private and industry sources have not bridged the gap.

Second, there is a danger to the support group that has developed since 1978 that supports the SIDS-prone infant. Many infants receive monitoring as a result of State-funded Medicaid programs. Through the federally funded block grant programs, these funds are supposed to flow with some degree of uniform clinical care and reimbursement criteria to patients in each State. At the present time, there are major disparities in the State infant monitoring reimbursement programs.

While I cannot overemphasize the need for additional Government funds for SIDS research, I must emphasize that I certainly realize the private sector's obligations to pick up where Government funding falls short. I can assure you that I am personally working toward attempting to unite various charitable SIDS organizations nationally so that fundraising can be accomplished in a systematic and focused manner, as is done for other charitable organizations such as cystic fibrosis and muscular dystrophy.

However, I cannot report that we have completed that task, and even when united, the needs for SIDS research will outpace charitable sources for some time in the future. I strongly recommend that the Federal Government commit at least $2 million annually to support research efforts. This is less than 2 percent of the total annual cost for managing the at-risk infants to the health care system today.

The international conference made it clear that there are, in fact, infants who are at high risk to die of SIDS. It is also clear that the only available approach to prevention that has some support at this time is the use of home monitoring programs. Unfortunately, it is difficult in the current health care climate to provide these programs and this kind of care to all infants in need, regardless of socioeconomic levels. However, I can say that a great deal of progress has been made through Federal and industry efforts in controlling the spiraling costs of health care and in moving health care toward the lower cost providers.

Of course, one of these low cost providers is home health care, and it is vital that the home health care remain an alternative to hospital care. But, the problem is that many home care dealers are currently finding it unprofitable to support home monitoring programs due to the difficulty in obtaining fair and equitable reimbursement for their Medicaid patients. If the reimbursement problems related to home monitoring are not stabilized, then the alternatives for these infants is hospitalization at costs of 20 to 30 times higher on a monthly basis. Therefore, I certainly think the home monitoring program problems that are beginning to develop because of the lack of adequate reimbursement standards from State to State is worthy of congressional examination.

Mr. Chairman, I want to thank you for the invitation and I speak, I am sure, for the rest of the panel. It has been a pleasure and I hope it has been informative.

[The following background information was furnished for the record:]

PARKER H. PETIT, CHAIRMAN, CHIEF EXECUTIVE OFFICER, HEALTHDYNE, INC.

Parker H. Petit, a native of Atlanta, Georgia, is Chairman of the Board and Chief Executive Officer of Healthdyne, Inc., an international diversified medical products and health care services company.

After losing his second son to Sudden Infant Death Syndrome (crib death) in 1970, Petit resigned his position as an Engineering Project Manager for the Lockheed-Georgia Company of Marietta, Georgia and founded Healthdyne, Inc., where he developed the world's first home physiological monitoring device, now used worldwide in the management of infants at risk for SIDS.

Since that time, Healthdyne has become a $184 million international corporation with a diverse product line that ranges from critical care equipment for hospital use to a full complement of therapies for home health care. Healthdyne's stock is traded on the national over-the-counter market under the symbol HDYN.

Petit was born on August 4, 1939. He earned a Bachelor's degree in Mechanical Engineering, and a Master of Science in Engineering Mechanics from the Georgia Institute of Technology and an MBA in Finance from Georgia State University. He served with an aviation unit of the United States Army, attaining the rank of first lieutenant.

He is the author of a number of papers, including "Industry Perspective—Apnea Monitors for Home Use," presented in 1988, and a textbook, "Primer on Composite Materials," published by Technomic Publishing Company in 1969.

He was the recipient in 1981 of the Humanitati A Le Plaisir D'Attribuer, a humanitarian award presented by La Societe Francaise of Charleston, S.C.

Petit is Chairman of the Board of the American Sudden Infant Death Syndrome Institute and a member of the Board of Directors of the Georgia Cystic Fibrosis Foundation. He is a member of the board of directors of Hybridoma Sciences, a biotechnology company; Atlantic Southeast Airlines, a regional airline; and The Advanced Technology Development Fund, a venture capital fund.

He is a member of the Cobb County Chamber of Commerce and the Health Industry Manufacturers Association. A licensed commercial pilot, he enjoys flying as well as oil painting, skiing, golf and tennis. He is the father of two teenage children.

Mr. GARCIA. Thank you very much.

I would just like to say to all of you how deeply appreciative we are for your coming today. We all share something in common. I am sorry that we don't have time for questions, but we will be submitting some questions to you and would appreciate your responding to them and getting those answers back to us as soon as possible.

Again, on behalf of the committee, we thank you very much for being with us.

Ms. REITER. Thank you, Mr. Chairman.

Mr. GARCIA. The third panel consists of parents who have suffered losses of their children to SIDS and have come forward boldly to share with us the personal impact of SIDS. The panelists are Jennifer and Ken Wilkinson from Great Falls, VA, and Sherry and Ronn Waller from Dallas, TX. Would you be kind enough to come up.

You have been waiting for quite some time. Have you worked out an arrangement as to which couple will go first?

Mrs. WILKINSON. Yes, I will go first.

Mr. GARCIA. Fine.

STATEMENT OF JENNIFER AND KEN WILKINSON, SIDS PARENTS, GREAT FALLS, VA

Mrs. WILKINSON. I am Jennifer Wilkinson and this is my husband, Ken. We lost our third child last December.

The story of our daughter, Larkin Adelle Wilkinson, is similar to that of over 7,000 children in this country each year. It is the story of the short life and sudden death of a person denied the possibility of a future. It is the story of pain, struggle—and in our case, survival—of individuals, a marriage, and a family. In all cases, it is a story which ends with questions: Why did our baby die? Could it have been prevented? What is this insidious killer called SIDS?

At birth, Larkin was pronounced healthy and normal by her doctors, and subsequently at home we made our own private pronouncements on her utter perfection—she was beautiful, good natured, and ours. She seemed to develop normally, growing stronger and more alert with each passing week. She learned to hold her head up and turn over on schedule and by Christmas she had reached that delightful age of 3½ months, when alertness turns into real curiosity and smiles often become those memorable first laughs.

The day after Christmas I found Larkin dead in her bassinet. No words can adequately describe the shock, horror, and pain of a parent at such a moment. To hold the cold stiff body of your infant offspring is to see in one unexpected blow your own future chapter deleted. To lose a baby whose sole source of nourishment had come from your own body, as in my case, is something akin to amputation.

The longer term repercussions from such an event are endless. In our case, we had to deal with our two older children's reactions. Our 6-year-old, who had just entered the first grade with enthusiasm and excitement, suddenly slumped into apathy and depression. Our younger girl had recurring nightmares and endless fears. "Can I get SIDS? Am I old enough to die? How many birthdays do I have left?"

The strain on our marriage was intense. While each of us was craving the support and comfort of the other, the effort of merely maintaining one's own equilibrium precluded the ability to give and to support, and the anger that always accompanies such a tragedy was a constant source of friction.

We had to deal with the reactions of others as well. We have discovered that there are those who are made uncomfortable by our pain and look to us for help in social situations. We continue to face the casual "how's the baby" from those who somehow did not hear the news at the time.

But the hardest single aspect of the experience has been learning to live with the hole left in each of our hearts by Larkin's absence. To think that this story repeats itself on the average of 7,000 times each year in this country, 1 baby every hour. I shudder to think that at this very moment some mother somewhere may be discovering the lifeless body of her beloved infant. It heightens my sense of urgency to know first hand what further pain and struggle that mother and her family have ahead of them.

Why, then, hasn't SIDS become a burning issue in this country? Why has research been progressing at such a terribly slow pace? Why is so little money going into a cause so worthwhile?

I think there are several explanations. One reason is that the general public remains ignorant about SIDS. Other than those who have had the misfortune of a first- or second-hand experience, very few people know the striking facts—that it is the No. 1 killer of infants in the first year of life; that there is no detecting it; that it continues to happen with the same cruel regularity day after day, month after month, year after year.

The figures are even more shocking when examined next to those of the causes which have, for one reason or another, come under closer public scrutiny. Muscular dystrophy, for example, thanks to Jerry Lewis' monumental efforts, receives millions of dollars each year from public and private sources. Everyone is familiar with "Jerry's Kids," the TV specials, the donation boxes in grocery stores.

Muscular dystrophy kills one-tenth the number of people per year that SIDS does.

AIDS is the most publicized disease just now, and also receives major financial support. As of August of this year, AIDS had not yet killed as many people total as SIDS does every single year.

Why, then is SIDS so overlooked? Do we value the lives of our babies so much less than those of others? Would the public concern be aroused if such an ailment struck our country's 5-year-olds or 10-year-olds or 20-year-olds? Surely we realize that to lose 7,000 fresh young minds per year is to seriously deprive the country of one of its greatest natural resources.

Why did Larkin die? Could it have been prevented? What is this insidious killer called SIDS? Let us hope that through further public awareness and research some of these questions will be answered. For the love of Larkin and all the other babies, I pray it will be so.

[The following response to written questions was received for the record:]

To Jennifer Wilkinson

1. Were you aware of SIDS before Larkin died?

2. Why should the Federal Government take on the responsibility and the financial burden of finding the cause and prevention of SIDS?

1. Before Larkin died, I had heard of "crib death" and had probably heard the term SIDS, though I didn't know what it stood for. I had never known anyone who had lost a baby to SIDS and had no idea how common it was. Since learning more about SIDS myself, I have become increasingly aware of the general public's lack of knowledge. Even many educated and well read people often believe there is a connection to one thing or another—breastfeeding versus bottle feeding, overbundling, sleeping alone versus sleeping with a parent . . . Indeed it is human nature to require some form of logical explanation for such an outrageous occurrence rather than accepting the awful fact that virtually nothing is known about the cause.

2. In spite of the fact that SIDS is the number one killer of infants in the first year of life, there is very little research being done either with public or private funds. There are basically two reasons for this sad state of affairs. The first is that the study of SIDS necessarily involves that of pathology rather than medicine since there is no illness preceeding the death. This automatically offers more of a challenge to researchers than when patients with symptoms are available for study thus

limiting the number of scientists interested in undertaking such a project. The fewer the number of requests for money, the fewer offers there will be. The second reason for the painfully slow progress with SIDS research is the lack of public awareness. The general public does not know enough about it to consider it a threat to them, when in fact, one baby in 500 is fairly high and all expectant mothers are at risk. Further public awareness would trigger more interest and thus more research.

If the federal government were to become involved, a national effort to break through the SIDS mystery could be launched. Through the Center for Disease Control, a uniform system of reporting autopsies and a specific national set of requirements imposed on the individual states medical examiners offices could lead to more accurate information on a broader scale than presently available. Surveys on larger numbers of SIDS victims would then be possible.

The federal government is the only body which has the financial resources to underwrite a program on this scale. Such funding could be done on an indirect basis as is the case with the Orphan Drug Bill thus attracting the private sector with the tax credits necessary to recover some of the cost.

STATEMENT OF SHERRY AND RONN WALLER, SIDS PARENTS

Mr. WALLER. Mr. Chairman, my name is Ronn Waller from Dallas, TX. This is my wife, Sherry. Sherry has been a registered nurse for over 8 years and has specialized in cardiac intensive care. She holds two degrees in nursing and I, myself, hold three degrees in chemistry, psychology, and mathematics.

I would like to introduce you to our son, Blake Christopher Waller, and I would like to tell you a little bit about him.

We fell outside of every category that was previously mentioned except for one. Blake was a little boy. He was born November 21, 1984, at Medical City Hospital in Dallas, TX. He was delivered by natural childbirth and was extremely healthy from the very beginning. At birth he weighed 8 pounds, 11½ ounces and was 21½ inches long, hardly an underweight at birth baby. His learning and maturation process amazed his mother and I and even his pediatrician by its rapid progress.

After 2½ months we hired a professional housekeeper and nanny, and Sherry resumed her career. Since her office was so close to the house, she would very frequently each day go home to visit him and play because he was so playful and so happy all the time. And I was the same way toward him. Blake and I were in love at first sight and there seemed to be a special bond between my son and I.

On the morning of March 6, 1985, we awoke to another day, as we always did. I went into Blake's room to give him a kiss before going to work. He awoke in his usual pleasant mood, laughing and smiling. His nanny arrived on time and Sherry kissed her precious child for just for the day, she thought, before going to her office.

At 1 p.m. Sherry called home. Nanny put the phone to Blake's ear, and when he heard her voice he started cooing and laughing, as he always did, because he recognized her. Then at 2 o'clock Sherry received a very frantic call from home. The message was, "Sherry, Blake's not breathing." The bluntness of the message took several seconds to sink in. Sherry frantically tried to explain how to do CPR and mouth-to-mouth resuscitation.

Suddenly the phone went dead and Sherry panicked. She thought, "She's overreacted. She's left him alone and he's not breathing." She immediately threw the phone down and rushed home. Thoughts racing through her mind were that there must be some mistake. He's OK. When I get there he'll be all right. It was just something she didn't understand.

But when she pulled into the driveway she encountered a sight that was very frightening. It's one that I pray none of you ever see. An intensive care ambulance was parked there and our baby son was sprawled in the back. One medic was trying to breathe life back into his limp body while the other was doing heart compressions, trying to restart his heart. When the paramedics saw Sherry running up to the driveway, they slammed the door shut.

Several of the neighbors were there trying to reassure her, and suddenly the paramedics yelled "Let's go." Sherry thought, "Thank God, Blake's alive." They still wouldn't tell her anything. They wouldn't say that he was OK.

The trip to the nearby emergency room at the hospital took only a few minutes, but it was like slow motion. Someone at her office called me as all this was happening and I raced across town as fast as I could. When I arrived, we sat in the emergency room and waited. We cried, we begged, and we prayed, that our only child would be spared. I was literally numb. How could this happen to Blake, who was only 3½ months. He was a picture of health.

Forty-five minutes later the doctors came to tell us that after multiple doses of strong cardiac drugs Blake had a heartbeat, but he was still not breathing on his own and they feared there might be brain damage because of lack of oxygen.

We rushed him to the intensive care unit at Children's Medical Center and asked the doctors on the way if there was some signs of vomiting or some signs of something abnormal because we wanted to blame something that we could really understand. They said there were no signs, that he was a perfectly healthy baby from birth to that moment, and there was no reason to believe that he had succumbed to some other problem.

They let us visit him in the ICU as frequently as we liked. We stayed there all night long. We would go in and talk to his lifeless form on the bed and read the sign above his name that said "Blake C. Waller, 3½ months, respiratory arrest." The facts hanging over his head shocked me into simplicity. We stayed all night looking for some improvements. There was none. The next morning the doctors came and told us that his brain waves were flat, that he had no brain activity. He hadn't taken a breath on his own since the day before.

Someone, some thing, had stolen our healthy, intelligent baby from our lives. We asked the doctors what the diagnosis was and they said sudden infant death syndrome. It strikes quickly, quietly, there is no detection, and there is no known cure. Your baby is just clinically dead. Very simple facts, too simple. But that's all we know about SIDS, except that it does take the lives of some 7,000 infants in the United States each year.

Sherry and I clung to each other. We couldn't believe what was happening to our lives and to our future. You know, why was our baby son lying there connected to all those ghastly machines? We didn't have the answers, and shockingly enough, neither did the experts. Our son was dead and no one knew why.

That evening they moved Blake to a private room so that we could be with him a few last moments. The doctors told us that we had to make the decision to disconnect the respirator. We prayed to God not to have to make that decision. We wanted time just to stand still. We felt if we could just keep him there on the respirator, where we could see him and touch him, that everything would be OK in time. But they said there was absolutely no hope of recovery and that we had to do what we had to do.

At 10 p.m. that night the nurse rearranged all the equipment so that Sherry could hold him one last time and rock him. Then I took Blake tenderly from her arms and held him and gently rocked him to sleep for an eternity. For 3½ months I had rocked him to sleep at that very time, at 10 o'clock each night.

We left the hospital and we left our baby son. Why had he lost his life? Why couldn't the doctors give us a reason for that elusive problem? Money. Doctors, medical examiners, and counselors alike told us the problem was money. Why can't we have more money available for such a horribly devastating problem as SIDS? I can't help but think that if a few dollars more had been available, that Blake would still be lying asleep in his soft crib in the room and be with us today. If we had all worked together in providing research funds, we might have found the answer. Why can't we protect the innocent, unkowing babies of our world? Because of money. We need more funds to do the proper research and development to find the answers to so many questions.

Initially, the death of our son had an impact on our lives that I can only say like our whole world had collapsed. Sherry would automatically go into his room each morning to pick him up, but the crib was empty. Blake's car seat had been removed from her car and she no longer had her sweet companion to go with her each day on her errands.

Sherry and I no longer had the pleasure of rocking Blake to sleep each night. The desolation and isolation were intolerable. We actually contemplated suicide to join our son, we were so lost. We sank to the depths of despair and hopelessness. We had so many questions, but no one had the answers. We couldn't find comfort in any direction. Our baby was dead and no one knew why. We kept wondering, how long can this silent killer attack our children before we take the concentrated effort to protect those who can't protect themselves.

All of our questions seemed to be answered with one word—again, money. Why hasn't someone done something to increase the funds allocated for SIDS research? Why don't we have enough money to save babies' lives? A baby can be healthy, happy, and smiling, and 60 seconds later be brain dead on a respirator. What is wrong that we can allow this to happen?

Our initial reaction of desperation was replaced with anger, which soon turned into constructive actions to try to do something, because we felt that we, Ronn and Sherry Waller, had to do something to attack this gigantic problem.

The only way really to be sure of winning this battle is for us all to work together and fight together. I think we're at war and we have to raise an army. We have to fight it together.

SIDS is the greatest killer of infants in this country, in my opinion, and medical science suggests it is the greatest killer of infants in the history of the world. It must be stopped. When we stop SIDS, we will also stop the thousands each year who cry, "Our baby is dead and we don't know why."

Thank you.

Mr. **Garcia**. Thank you very much.

Just let me say to the both of you that I really commend you. I know how difficult it has been because it was difficult for me to listen, because I think we all have relived the same moments together. I really want to thank both of you. I think it is very courageous of you to come forward.

In terms of politics and Government, the bottomline really breaks down to the experience. It's what we all have gone through that makes our hope in combating this mystery possible to conquer. I would say to you two couples that we will do everything humanly possible to try and alert the Congress and the Senate to the needs for increased funding to combat this. I can assure you that as long as I'm a member of this body that I will be a very, very active member, and that your testimony today will help us a great deal in making sure that other Members of Congress understand not only our loss, but our sense of inadequacy when we don't know why. I think all of us have felt that. I thank you very much for being with us today.

I would just say that we're going to keep this record open for questions and answers. If those answers can be submitted to the staff of the Census and Population Subcommittee we will make sure it is entered into the record.

I thank everybody for being with us today.

[Whereupon, at 12:45 a.m., the joint hearing was concluded.]

[The following statement was received for the record:]

Statement of Lewis P. Lipsitt, Professor of Psychology and Medical Science, Brown University

Mr. Chairman, I am Lewis P. Lipsitt, Professor of Psychology and Medical Science and Director of the Child Study Center at Brown University. I am pleased to have this opportunity to present testimony on research on Sudden Infant Death Syndrome (SIDS) on behalf of the Federation of Behavioral, Psychological and Cognitive Sciences. The Federation, formed in 1980, is a coalition of 13 scientific societies with combined memberships of over 90,000 behavioral scientists.

I have been involved in infancy research since 1957 and SIDS research since 1974. In addition to this testimony, I am submitting my 1979 American Psychologist article on SIDS research. */

Research on the causes of Sudden Infant Death Syndrome (SIDS) has concentrated historically principally on the organic conditions preceding death. The assumption has been, quite understandably, that there must be some underlying illness which will be discovered eventually. Because SIDS is a "residual diagnosis" (the medical examiner or pathologist must certify that no known cause of death has been found), parents and physicians are inevitably perplexed by the situation. Unfortunately, recriminations are common.

In the absence thus far of any specific physiological mechanism to which SIDS can be definitely tied, some of the most hopeful research stems from the epidemiological or, more accurately, actuarial data on the phenomenon of SIDS. This line of research has documented those conditions of the baby's fetal development, birth circumstances, familial environment and social milieu that may be related to the SIDS outcome. Typically, the hospital records are explored to find higher than usual incidences of particular prenatal and perinatal conditions, such as premature birth, low birth weight, low socioeconomic factors, the need for resuscitation at delivery and maternal smoking. Such studies have in fact confirmed the relevance of these conditions as somehow being involved as "setting conditions" in SIDS. As can be readily noted, many of the conditions that have been so implicated do relate to life style and the social welfare of the family.

To be sure, not all of the factors that can be confirmed as statistical correlates of SIDS will be found in any given case of crib death, and indeed most infants who possess multiple risk factors that are associated with SIDS do escape from the fate for which they seem strongly destined by actuarial counts. Nonetheless, the data have value in suggesting that certain populations of infants (e.g., those who live in inner-city poverty) are in greater jeopardy than others. It should follow that 1) the mechanisms and processes by which these statistical verities emerge should be discoverable with appropriate scientific effort and 2) interventions may be implemented to reduce the increased likelihood of SIDS in the at-risk populations of infants. We need to know more about what happens naturally in those who have the risks but are somehow immunized by extenuating circumstances and escape death.

*/ Retained in subcommittee files.

Sometimes the presentation of findings which suggest that style of living may be implicated in the deaths of infants causes consternation. Few of us would like to believe that the behavior of parents or the milieu in which infants are raised, which the parents may not be able to alter, can be legitimately tagged as contributors to death. However, we must look beyond the accusatory paranoia which so frequently accompanies the SIDS phenomenon and try to find those fortuitous and seemingly benign conditions in the lives of families and infants which appear to be implicated as SIDS precursors. Smoking behavior is one such condition.

No apparent and deliberate "harm" has occurred in SIDS cases; the very definition of the diagnosis rules out accidents or tissue injury of any sort. The argument that we must look carefully at the psychophysiological condition of the baby and the biobehavioral factors accompanying development during the 2-4 month vulnerable age period carries with it no suggestion that parents are "responsible" for the demise of their SIDS infants. At the same time, we must explore the possibility that SIDS may be the culmination of a developmental failure of some sort, perhaps implicating the learning processes of babies and, possibly, inadvertent failures of the environment to provide the stimulation which is required to enable the baby to become invulnerable to certain types of developmental stresses.

To assert that SIDS may be the result of a special type of learning disability would go beyond available data, but the possibility as a hypothesis has considerable supportive, circumstantial evidence. The short version goes like this: There is the possibility that crib death involves a failure of a sufficiently strong learned response to develop, involving defense of the respiratory passages from occlusion. Babies are born with a respiratory occlusion reflex that, with varying strengths, tends to protect newborns from smothering. (Few babies in the first month of life die of SIDS.) The strength of this reflex is easily tested in the first month of life, and there are large individual differences in it. By 2-4 months of age, this reflex, probably largely subcortically mediated like many other reflexes with which the baby is born, has waned considerably. The initial congenital reflex must be supplanted eventually by a largely cortically controlled, "voluntary response." This comes about in part through a conditioning process on the basis of the initially unconditioned reflexive self-protective behavior. The child's pptection is thus assured through the acquisition of a developmentally graded adjunct to the initial reflex. The baby comes to know what to do, as it were, when threatened with respiratory blockage.

Infants who succumb to SIDS often have respiratory blockage (as from a cold) just before their demise, and their deaths often take place in the night when their thresholds for self-protective activity are at an ebb.

Perhaps, too, their struggle for air is not as easily heard by others in the nighttime. These types of "surrounding conditions," when coupled with the possibility of a special kind of learning disability in infants who succumb to SIDS, strongly suggest that more research is needed into the likely interaction that exists in SIDS groups between organic deficiencies, on one hand, and non-organic, functional, environmental conditions, on the other.

The proposition can be reasonably made that SIDS victims enter life with a surplus of specific risk conditions, many of which have already been identified (e.g., low birth weight, smoking mothers), and these conditions conspire with subsequent environmental events (e.g., poverty conditions) which place the infant at still greater risk. Specifically, infants who succumb to SIDS may be those who enter life with an inadequate repertoire of unconditioned or constitutional responses, such that inadequate conditioning takes place based upon, for example, the respiratory occlusion reflex. As a consequence, the infant may become a victim of a special type of learning disability such that he or she is not capable of engaging in appropriate self-defensive behavior when confronted with respiratory occlusion, perhaps at night when sensitivity to such threats is reduced by drowsiness or sleep.

It would follow from this set of presumptions that special training of vulnerable infants might help to reduce the risk of SIDS. Research is needed which would test this particular biobehavioral hypothesis and other hypotheses stemming from a closer consideration of psychological and environmental perturbations that may be implicated in SIDS. Indeed, we would suggest that a major direction for research funding in the future should be intervention studies of environmental, behavioral and socioeconomic factors.

I want to thank you for the opportunity to present testimony. If I can be of any further assistance, please do not hesitate to call on me or Federation staff.

DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Secretary

Washington, D.C. 20201

[illegible] 25

Ms. Lillian Fernandez
Staff Director
Subcommittee on Census and
  Population
Committee on Post Office and
  Civil Service
House of Representatives
Washington, D.C. 20515

Dear Ms. Fernandez:

Enclosed are the responses of Ms. Geraldine Norris, Director, Sudden Infant Death Syndrome Project, Division of Maternal and Child Health, Health Resources and Services Administration, to the questions which were sent to her for inclusion in the record of your November 14 hearing.

Sincerely yours,

Edward P. McGroarty
Legislative Officer

Enclosures

1. A. What are the reporting requirements for Maternal and Child Health (MCH)-sponsored SIDS services in the States (how frequent are reports; what data do they include; by whom are they reported)?

The Omnibus Budget Reconciliation Act of 1981, Title XXI, subtitle D amended Title V of the Social Security Act to establish the MCH Block Grant. Section 506 of the Social Security Act requires that each State receiving MCH Block Grant funds prepare an annual report for the Secretary of the Department of Health and Human Services.

In keeping with the intent and spirit of the block grant approach, the Department has not established specific reporting requirements. However, a general guidance format for preparing annual reports has been provided to State health authorities (Enclosure 1). .

1. B. What is the procedure for reviewing the reports?

The annual reports are reviewed in the Department's regional offices by program representatives who are familiar with MCH programs in the states of their region. The reports help them to maintain their familiarity with State programming and to guide them in their consultation with states. Control office staff periodically review the reports as needed.

1. C. What is the relation between the reports and plans for future action on SIDS within MCH?

Since the Department's MCH representatives do not have a role in directing program activities in the States, the Department's regional office representatives use the information in their consultation activities with the States. SIDS Central Office representatives use the information in their discussions with regional representatives and for a number of management and administrative purposes including identifying national issues, priorities and approaches; coordinating activities with organizations and agencies in the public and private sector, and sharing information nationally.

1. D. Aside from formal reporting, what other sources of information does the Department have on the status of SIDS services in the States?

The majority of State Health agencies voluntarily report selected types of MCH service data to the Public Health Foundation, formerly known as the Association for State and Territorial Health Officials Foundation. Their most recent publication entitled Public Health Agencies 1983: Services for Mothers and Children contains summary data from 48 States. Of these, 44 State health Agencies reported service data on SIDS. Two excerpts from this publication are submitted for the record (Enclosure 2 and 3).

On May 7, 1984 the United States General Accounting Office published a report to Congress entitled Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration. Information from 13 states concerning the MCH program and including the SIDS program was collected and analyzed. The 13 States were California, Colorado, Florida, Iowa, Kentucky, Massachusetts, Michigan, Mississippi, New York, Pennsylvania, Texas, Vermont and Washington. In these States the SIDS expenditures for 1983 amounted to 0.2 percent of their total MCH expenditures. The findings indicated an overall general decline in SIDS activities. Two excerpts from this report and submitted for the record (Enclosures 4 and 5).

Because of the substantial interest concerning the status of SIDS programs in the States in the first years of the MCH Block Grant environment, a study of the 50 States, 6 territories and the District of Columbia was conducted in 1984 by the Association of Maternal and Child Health and Crippled Children's Programs. All jurisdictions except Montana and the territories reported that they provided or arranged for SIDS activities whether or not they had a distinct and identifiable SIDS budget or project. In general, about 43 percent of the States reported a decrease in funding between FY 81 and FY 84. About 12 percent had increases of 10 percent or more; 29 percent had remained unchanged; and for 16 percent of the States the level of funding for one or both years was unknown. In summary, services such as identification of infant deaths, confirmation of SIDS by autopsy, and counseling for families continued to be the keystone of the State programs for SIDS. Conversly, educational programs; community input; and data collection and analysis efforts were on the decline. The majority of State Health agencies also indicated that they were involved with prolonged infantile apnea, an associated problem of SIDS. Their involvement ranged from the establishment of criteria and guidelines for infant apnea services to the direct provision or support of services for families with infants at high risk for experiencing prolonged apnea.

Other less formal sources of information include ongoing communication with other Federal programs concerned with various aspects of SIDS; working relationships with private and voluntary organizations concerned with the problems of SIDS; site visits and periodic communications with the Federal Regional offices and State health agencies; participation in relevant conferences; review of current literature; and, close collaboration with the National SIDS Clearinghouse.

2. A. Using the most complete and current information available, what is the status of MCH-sponsored SIDS service projects in the States?

Many State MCH agencies do support a variety of SIDS activities for their populations which may or may not resemble the SIDS projects supported as grants prior to the implementation of the MCH Block Grant program in 1982. Therefore, rather than define the current status of MCH sponsored SIDS projects, it now is more accurate to discuss the current status of State MCH supported SIDS program activities.

Overall, State MCH support for SIDS program activities are declining. States are compensating for this by appealing to other concerned agencies, organizations and private funding sources for additional support and collaboration. As a result, some of the major SIDS program components defined in the 1970's have declined, some have remained constant and others have intensified within any given State.

Autopsies in the mid 1980's are being conducted with equal or greater frequency than in the late 1970's in more than 75 percent of the 57 political jurisdictions. Only 2 States report that the incidence of autopsies in their States has decreased.

Over 60 percent of the States report that the SIDS educational activities in their areas continue to be offered to a wide variety of professional groups who encounter SIDS families and to the general public. About 26 percent of States report that their SIDS educational activities have declined. More often than not, these programs are a collaborative effort of the State staff and the voluntary parent organizations or they are conducted independently by the parent organizations.

Only one-third of the States have active advisory councils or other means of formal inter-agency and citizen collaboration.

In about 77 percent of the States the SIDS Program activities receive support from the MCH Block Grant Program. With a few exceptions, the amounts have been declining over the past 4 or 5 years. The programs have been supplemented by State general funds, and private services.

2. B. How many states have projects?

Sudden Infant Death Syndrome program activities are supported in 46 States by MCH Block Grant funds. In five States SIDS services are not supported with MCH Block funds but they are available from neighboring States or they are supported by private organizations. Information is not available from the six remaining political jurisdictions.

State MCH Block Grant Funds
Supporting SIDS Activities

1. Alabama
2. Alaska
3. Arkansas
4. California
5. Colorado
6. Connecticut
7. Delaware
8. District of Columbia
9. Florida
10. Georgia
11. Idaho
12. Illinois
13. Indiana
14. Iowa
15. Kentucky
16. Louisiana
17. Maine
18. Maryland
19. Massachusetts
20. Michigan
21. Minnesota
22. Mississippi
23. Missouri
24. Montana
25. Nebraska
26. New Hampshire
27. New Jersey
28. New Mexico
29. New York
30. North Carolina
31. North Dakota
32. Ohio
33. Oklahoma
34. Oregon
35. Pennsylvania
36. Rhode Island
37. South Carolina
38. South Dakota
39. Tennessee
40. Texas
41. Utah
42. Vermont
43. Virginia
44. Washington
45. West Virginia
46. Wisconsin

States that do not
support SIDS
activities with MCH
Block Grant Funds

Arizona
Hawaii
Kansas
Nevada
Wyoming

No data
available

American Samoa
Guam
Northern Marianas
Puerto Rico
Trust Territories
Virgin Islands

2. C. What services do these provide? How many, for example, provide informational counseling services for the parents of SIDS victims? How many provide training and education for health care professionals, law enforcement professionals, and the general public?

A basic SIDS program of services includes identification of possible SIDS deaths; confirmation of SIDS by a death investigation including an autopsy; information and counseling for the family survivors; educational programs for professionals who encounter SIDS families; and, public awareness activities.

Information and counseling services for families are available in 48 States by physicians public health nurses, social workers or others in public agencies, or by peer counselors from private organizations. One State has had no informational program during the past year. There is no data available for 2 States and 6 other political jurisdictions.

2. D. How much money do they spend on an average? What is the range in amounts spent?

An accurate accounting of expenditures by all States for SIDS program activities has not been available since the SIDS program was integrated with the MCH Block Grant Program.

The following was reported in the Maternal and Child Health Block Grant: Program Changes Emerging Under State Administration, a GAO report prepared for Congress on May 7, 1984.

EXPENDITURES FOR SUDDEN INFANT DEATH SYNDROME (SIDS)

				Change a	
State	1981	1982	1983	$	%
	(000 omitted)				
Colorado	$ 57	$ 43	$ 37	$ (20)	(35)
Florida	78	90	64	(14)	(18)
Iowa	43	40	41	(2)	(5)
Kentucky	62	52	40	(22)	(35)
Massachusetts	120	180	158	38	32
Michigan b					
Mississippi	0	18	22	22	c
Pennsylvania	118	125	220	102	86
Texas	170	18	0	(170)	(100)
Vermont	20	19	23	3	15
Washington d	117	111	85	(32)	(27)
Total	$785	$696	$690	$ (95)	(12)
California		$120	$ 0	$(120)	(100)
New York		300	90	(210) e	(70)
Total		$420	$ 90	$(300)	(79)

a Period of change for first 11 states is 1981-83; for California and New York it is 1982-83.

b Michigan is excluded due to lack of comparable data.

c Percentage change cannot be calculated.

d Total SIDS expenditures could not be identified because all related costs were not recorded separately and were not readily available. The identified expenditures include data from one service provider during the 3-year period.

e New York funding change may be overstated, although the declining trend is real. Part of this decline resulted from a change in the way the program was accounted for in 1983.

2. E. **How many people in America live in states or parts of states in which there are no SIDS projects? Are there plans, on the state level or within MCH, to establish programs in these areas?**

Using the 1983 population reports produced by the U.S. Bureau of Census, approximately 12,475,400 people live in areas in which there are few or no SIDS program activities. They are as follows:

States With No MCH Supported SIDS Programs	Population
Arizona	3,959,000
Hawaii	1,023,000
Kansas	2,425,000
Nevada	891,000
Wyoming	514,000
American Samoa	34,000
Guam	116,400
Northern Marianas	18,200
Puerto Rico	3,267,000
Trust Territories	124,000
Virgin Islands	103,800
Total	12,475,400

At this time, each State has the responsibility to identify and prioritize the health problems of their populations; and, to allocate funds and other resources to respond to those selected priorities.

3.A. **What changes have taken place in SIDS projects since the implementation of the Maternal and Child Health Block Grant in Fiscal Year 1962?**

The following indicate some of the major changes that have taken place since the implementation of the Maternal and Child Health Block Grant in Fiscal Year 1982.

In Fiscal Year 1981 there were 46 Federally supported SIDS projects in 41 States. At this time each State is responsible for determining whether or not to support SIDS activities. To the best of our knowledge, 46 States do conduct some SIDS activities, however, the range of services varies considerably. In many States the MCH Block Grant funds are supplemented by General State funds and contributions from private and voluntary services.

3. B. Which states have initiated or ended SIDS projects altogether? Which have initiated or ended projects in certain regions?

MCH Block Grant funds for the SIDS program in Hawaii were recently discontinued. The SIDS program activities have been curtailed and are being conducted by volunteers.

In Texas MCH support for the San Antonio SIDS project was withdrawn and in Pennsylvania MCH support for SIDS program in Philadelphia was terminated recently.

The State of Virginia is in the process of developing a coordinated Statewide SIDS program.

3. C. Which states, as far as you know, have had changes in staffing, budgeting, or availability of services? What have those changes been?

Almost all States, except Virginia where a SIDS program is being initiated, have experienced reductions in staffing and budgets. Generally, educational programs as well as data collection and analysis have been curtailed. While information and counseling have continued, the numbers of contacts with families and the period of time over which counseling is available have been curtailed. The numbers of infant autopsies being conducted continue to increase.

4. C. What is the trend in spending on SIDS services from 1974 to the present?

The following table shows the appropriation of funds for the SIDS program as authorized by the SIDS Act of 1974 (P.L. 93-270) and its ammendments. These funds were used to support grants for SIDS information and counseling projects in the States.

SIDS Appropriations 1975-1981

Fiscal Year	Appropriated Federal Funds
1975	$2,000,000
1976	2,500,000
Transition quarter	56,000
1977	2,000,000
1978	3,000,000
1979	2,802,000
1980	2,802,000
1981	2,802,000

In addition to the above, the Department consistently expended approximately $200,000 annually for national coordination, program development and information exchange activities.

In FY 1982, the SIDS program was consolidated into the Maternal and Child Health Block Grant program. Since then, comparable financial data across States has become more difficult to identify. Reports cited in response to question 1 indicate a general decline of expenditures by States for their SIDS programs.

At the National level SIDS activities continue to receive support through the Special Projects of Regional and National Significance (SPRANS) Program of the MCH Block Grant Program. In F.Y. 1985 approximately $675,000 of SPRANS funds supported 2 research grants, 2 demonstration grants and 3 other SIDS activities, including the National SIDS Clearinghouse. These activities have been described more fully in responses previously provided for the record.